

**THE SEARCH FOR A GOOD LIFE:
YOUNG PEOPLE WITH LEARNING
DISABILITY AND THE TRANSITION FROM
SCHOOL**

*A thesis submitted in partial fulfilment of the requirements for the Degree of
Doctor of Philosophy in the University of Canterbury*

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April 2014*

Education either functions as an instrument which is used to facilitate integration of the younger generation into the logic of the present system and bring about conformity or it becomes the practice of freedom, the means by which men and women deal critically and creatively with reality and discover how to participate in the transformation of their world. (Shaul, 1996)

The carrying capacity of a bridge is measured not by the average strength of its pillars, but by the strength of the weakest among them; and so is the “carrying capacity” of society, that is, its humanity and hospitality. Society is as much human as the life conditions of its most humble and least potent members. (Bauman, 2007c, p. 58)

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ACKNOWLEDGEMENTS

First and foremost I would like to thank Andrew and Caroline, two young people who I have the privilege to call friends and colleagues. Without their continuing personal and professional support, moral strength and insight this research journey would have been much less worthy.

I would also like to express my gratitude to the students and young people who participated in our study and provided such rich descriptions of the goals and aspirations for their future lives. Their overwhelming optimism drove the research process together with Andrew and Caroline.

I owe a very large debt of gratitude to my lead supervisor Associate Professor Dr. Missy Morton whose time and commitment sustained me through this long journey. Also thanks to my second supervisor Professor Garry Hornby for his support.

Last, but certainly not least, much love and thanks to my darling wife Jill and sons Nathan and Callum. I know you have endured much and given only unstinting support and sacrifice in return.

I dedicate this work to my father a true scholar.

ABSTRACT

This qualitative study is concerned with the transition process from school to post-school life for students labelled with learning disability in New Zealand. My interest is in understanding how a particular group of these young people can make a successful transition from school in their search for a good life, as they themselves judge this. I draw on critical social theory to position these young people within contemporary education and society, using a Disability Studies in Education (DSE) framework to understand learning disability as socially, culturally and politically constructed.

I draw on Zygmunt Bauman's critique of neoliberal hegemony and use of metaphor to understand how young people with learning disability are excluded in a contemporary Western society. Post-school outcomes identify very little useful tertiary education or paid employment; long-term reliance on family for living and housing; and extremely limited social networks, mostly founded on family members and paid or voluntary support workers. I argue that these young people are caught in a parallel education system that largely controls and manages them along a restrictive pathway from special education services in schools to special vocational and welfare services post school. The clear voice of the young people through the research findings demonstrates this is not what they want. They want the same opportunities as their peers without disability.

Andrew and Caroline, two young people with Down syndrome, and I formed a research team. We came together to explore, understand and respond to an exclusionary landscape during the transition process that I argue leads to unrealised lives. The study utilises a participatory action research approach. It is a collaborative journey and a transformative response to exclusion through what I describe as "the relational dimension." Further, it is a call to arms on behalf of a particular group of students who have been mostly excluded from rights, responsibilities and opportunities to contribute positively to their lives and the lives of others.

This thesis has been a journey of personal and professional, individual and collective discovery. Answers to the question of how young people with learning disability can transition towards a good life are to be found in how we fundamentally value this group of young people in education and society. Valuing can only occur if we recognise our

interdependence while acknowledging our unique differences. Only then will we truly provide the opportunities and support that we all need to move forward in our journey towards a good life.

This thesis will be of interest to young people; parents; education and social policy leaders; school leaders; career specialists; and all teachers, professionals and support workers in the field. Its findings and recommendations challenge “expert” and deficit constructions of learning disability. They have relevance for a collaborative “whole-school” approach to career and transition policy and practice for students with learning disability; importantly, however, they also have relevance for all students. Effective relationships are central to understanding how, through our relative interdependency; we can collaboratively make the journey towards a good life. Additionally, the thesis contributes to knowledge regarding how to meaningfully involve young people with learning disability in the research process through their lived and our shared experiences that provide ethical, methodological and procedural insights.

I develop two main arguments in this thesis. My first argument is that exclusion from educational opportunity must be exposed, challenged and rejected. Exclusion must be exposed in order to understand the unequal power mechanisms at play. Exclusion must be challenged, as the outcome of these unequal power mechanisms is that some students succeed and some fail. Exclusion must be rejected to make way for new relational, transformative education agendas. My second argument is that direct and meaningful involvement and collaboration by young people with learning disability in the research process will support practical solutions towards greater democracy in education and society. The ultimate outcome of democracy in education is a system where all students are valued and celebrated for their unique differences and stories, yet with recognition of their relative interdependency. All students are viewed as capable, purposeful, responsible and contributing. They are provided with the opportunities and support required to realise a good life, leading to active contribution and a sense of belonging in education and society.

CHAPTER 1: INTRODUCTION

This thesis seeks to understand how a group of young people labelled with learning disability can make the difficult transition from school to post-school life in contemporary New Zealand society. It describes the collaborative journey that was taken by our research team towards shared understandings in the social construction of learning disability. Importantly, it is also a call to arms on behalf of a vibrant, capable and insightful group of young people. As a teacher, I have listened countless times to the narratives of students with learning disability concerning their future lives. These narratives are dominated by concern and anxiety for the future on the one hand, and overwhelming optimism on the other. Often, when catching up with these young people and parents in the years after leaving school, I find that their narratives have changed little. They still have the same optimism and aspirations for their lives but appear no closer to realising them.

My experiences as a teacher working with students with learning disability over many years have often left me frustrated with a system in which the school to post-school transition is dominated by multiple processes, procedures and seemingly competing stakeholders (Dee, 2006; McGinty & Fish, 1992; Mittler, 2000; Smith & Routel, 2010). School staff always worked diligently and professionally at supporting the young person and their families within this complex transition process, but professional discourses usually appeared at the forefront of decision-making processes, while the parents' and – most significantly – the student's voices often appeared to be lost. My thoughts were that these professional discourses represented wider issues, particularly related to the policies and practices of inclusion, exclusion and special education. The transition process from school for students with learning disability in New Zealand appeared predominantly one of a move from special education services to social welfare and vocational day services (Bray, 2003; Mirfin-Veitch, 2003).

Establishing the context

In this chapter, I first provide a brief profile of each of the three research team members. Two young people, Andrew and Caroline, are the heartbeat that drives this participatory action research journey. As co-researchers within the research team, they introduce themselves in their words. I then describe the purpose of the study and provide a brief snapshot of the

policy and legislative context – how students with learning disability are educated in New Zealand – and begin to point to the tensions that I will expose and explore in detail through later chapters. This is followed by a description of the reality for students with learning disability leaving school in a New Zealand city. I outline some issues related to the transition process, as a precursor to the substantive exploration of the literature on transition and social responses to learning disability in Chapter 2, and I provide a brief general description of education in New Zealand.

I move on to locate the research within the field of Disability Studies in Education (DSE), aligning with DSE's critical stance in positioning learning disability as a social, political and cultural concern and construction. I therefore challenge approaches that view disability as an individual and biological "problem." I proceed to examine literature on the debates and dilemmas related to inclusion, exclusion and special education, drawing on key critical thinkers and educationalists including those from DSE perspectives.

Exclusion is a key theme that emerged from the findings of this thesis. In this chapter, I begin to consider the ways that students with learning disability are positioned by professional discourses and the implications for policy and practice. Particularly, I examine how students with learning disability fare in relation to career and transition education, asking whether pathways are opened up or restricted. In addition, I consider the pervasive influences of neoliberalism and the market on New Zealand education and schools. All these tensions and issues provide a complex environment for students with learning disability transitioning from school in a fluid, competitive, individualised and consumer-driven society. In this context, I briefly introduce the social thought and metaphors of Zygmunt Bauman, which I draw on in the findings and discussion chapters to position young people with learning disability in what he describes as "liquid modern" society (Bauman, 2000, 2006, 2007a). As the chapter draws to a close, I introduce the concept of a good life, turning to what I call the "relational dimension" as a strategy and toolkit for thinking about and locating the research findings and implications

Both our ways of knowing and what we know about learning disability have privileged the knowledge of professionals and academics (Nunkoosing, 2000). The capabilities of young people with learning disability are often left dormant and undiscovered. The voices,

perspectives and aspirations of young people with learning disability are lost within changing contexts characterised by often negative, unclear, contradictory and confused messages about learning disability, difference, inclusive education and transition. I argue that the perspectives and voice of young people with learning disability must be fundamental in resolving the issue of their continuing exclusion from educational opportunity as they transition from school in their search for a good life.

The contentious nature of what makes inclusive research and how to do it was an important aim of this research. The inclusive approach adopted was core to the research process and was evolutionary in nature. Inclusive research is evolutionary in the sense that it is exploratory, messy and risky; in many ways a journey into the unknown. It is evolutionary because it tackles fundamental debates about social inclusion, equity, justice and power. Central to my understanding of an inclusive approach in our research was the privileging of the young people's lived experiences in seeking shared understandings of how, why and in what way some people are included or excluded from society.

This research involved focus groups with students and young people with learning disability who were either still at school or had left school up to five years earlier. The young people's experiences and perspectives regarding the transition process were obtained over an extended period. Using the young people's narratives and drawing from my professional experience, related texts, policy and other documents, communications and a joint conference presentation, I examine and critique inclusive and special education, Western knowledge frameworks and transition-related policy and practice.

Background

As a teacher and practitioner researcher, I have over 30 years of experience in the United Kingdom and New Zealand, working in both secondary and special schools in classroom and senior leadership roles. My particular professional interest has been mostly in students at the margins of the education system – particularly those who have the label “learning disability,” which is a broad term that encompasses a heterogeneous group. In general, people with learning disability – whether school-age or older – have a long history of exclusion and marginalisation within education and society (Ballard, 2007; Bray, 2003; Chappell 1998;

Chappell, Goodley, & Lawthom, 2001; Goodley 1997, 2000, 2001; Johnson & Walmsley with Wolfe, 2010; Walmsley 1997). The education system often struggles with preparing and providing effective post-school pathways for these students (Dee, 2006; Mittler, 2007).

My professional experience and reading of the literature on learning disability point to the difficulty of translating the rhetoric of inclusive policy and legislation into real practical change in schools (Mittler, 2007). Schools are influenced by a multitude of stakeholders and tensions in the school to post-school transition process, so the field of inclusive education is one of the more hotly debated areas in education and social policy. As students with learning disability approach the end of their extended schooling, the immediate outcome of this complex transition phase becomes highly predictive of where they will spend the rest of their lives (Meadows, 2009). Transitions from school in New Zealand society today for young people without disability are generally driven by discourses related to the knowledge and consumer economies, neoliberalism and individualism (Nairn, Higgins & Sligo, 2012). Tertiary qualifications have become the government mantra and the young person's passport to well-paid employment, which brings with it increased control over the different aspects of life. Constructions of identity for young people – such as the “tertiary educated self” and “professional worker self” – form the narratives of successful transition in neoliberal policy. This thesis is interested in the lived experiences, narratives and identities of young people with learning disability and their position –or lack thereof – within this fluid, competitive landscape. Historically, constructions of these young people's identities have usually been articulated by other people, particularly professionals.

When I came to New Zealand and secured a teaching post in a special school in 2007, I was immediately struck by the fact that those students classified with high or very high support needs under the Ongoing Resourcing Scheme (ORS) could stay on at school until the end of the academic year that they turned 21. At the time, I thought that this meant there was probably nothing much for them after leaving school and was maybe a strategy for what one parent described as “putting off the inevitable.” My teaching experiences and conversations over the ensuing years with the young people, parents and colleagues have reinforced these suspicions.

Decisions by parents were often made on behalf of their young people, with the best intentions. However, these decisions were often made without the right information at the right time and from positions of fear and concern. Parents often took the perceived “safe option” of the day centre, where their loved ones could be supported during the day. The leap of moving from the safe and supportive environment of school to the “real world,” as one student described, it was seen as a step too far by most parents.

After a year at my school, I obtained a new role, which had been created in 2008 as a result of the realisation that over the next three years there were an unusually large number of secondary-age students coming through and leaving school. It was my job to figure out how best to support them in their transition from school. Around this time, I also became involved with a research project by a local trust and philanthropic organisation, the Wayne Francis Charitable Trust (WFT), who were examining systemic issues relating to this particular transition from school for students with disability. A literature review and wide consultation was undertaken. I co-conducted the focus groups and was co-author of a report and recommendations (Cleland, Gladstone, & Todd, 2008). As a result of the recommendations, the local Ministry of Education office collaborated with the trust and a group of local secondary and special schools to set up a transition service that was officially launched in August 2009. The service was called the Lead School Transition Service (LSTS). The service scope was to build capacity and capability of the participating schools to work more effectively with students with disability during transition, and I was appointed manager. I provide this background because it demonstrates my involvement as a teacher and researcher in schools, but also an insider understanding and presumed expertise on transition.

Two students involved as participants in the WFT research became co-researchers in the project described as part of this thesis. In the following pages, they introduce and describe themselves using their own word-processed narratives.

The co-researchers introduced



Figure 1: Andrew and Caroline – co-researchers

Andrew

My name is Andrew Dever and I want to write my own words about me for Colin's PhD.

When I left school I didn't want to go to Polytech because I thought it was just another school and I had enough of school. I went to a day centre and my friends there but I want more with my life like a job with money and travel and get married.

I have mum called Nancy dad called Chris and a brother called Edward and Annie my cat. My family is very important to me. They are always there for me and have helped me out lots. Edward is older now he lives in Auckland.

I wanted to do this research because way back when it started Caroline and me were in our last year of school and Colin was our teacher. We were leavers ourselves. Since this research I am friends with Colin's family now which is cool and we go out and drink beer and just hangout colin helped me a lot of times.

I am flatting at the moment which is great. When I first started flatting I was with people I didn't know and they were older and caused trouble to me. I didn't like it there and wanted to move. My parents help me and now I am with two friends I know one is my girlfriend. At the moment I am happy with what I am doing but would like a job to.

Being a researcher has helped me be more confident to know lots more people and them to know me more. I have been to lots of places in New Zealand and Australia and speak to lots of people of our research. We have done lots of conferences and talked to so many people about our research. This means people know how good we are with people with disability and to give us a chance.

The earthquakes in Christchurch had a big effect on me and the research. We lost our office and had to work in lots of different places. It was bad for me and everyone and people with disability. People with disability they want the same things that other people. People don't listen and so its difficult

Caroline

My name is Caroline Quick I am 24 years old and I am from England, i been living in New Zealand for 7 years now. I got a mum, dad, younger sister and my Nan. I like to hang out with my friends, bowling with a social club, shopping and listening to music. My future goals is to lose weight and it least to go down several clothes sizes like a 18 or 16, to get paid employment around cafe work like food prep or barista making coffee. But first I would like to do a course on how to make coffee and the art of it, before I get anything in employment. I just read an interesting book called people with intellectual disabilities towards a good life.

I have been to different conferences with Colin and Andrew and now different organisations too to talk about the findings of our research and how we can get other people in the state of the mind of what the research means to them.

The transition from school to post school life starting at the age of 14 has been critical but nothing has happened so I am hoping it will start soon if not I will be writing a letter to MOE to get a move on

I am an advocate with People First and I thoroughly enjoy it being part of the community and to see what's out there and to spread the word out there. Being an advocate is my passion and I want to be able to speak up for those people who can't be able to speak in their community, home, work, anywhere but the moral of the story is to be HEARD and have your say.

Back in England I lived with my parents and when I came to live in New Zealand I was with my parents again but I wanted to leave home and to go flatting in the community. I started my experience living in a flat with 2 older ladies I found it alright because I wanted my independence but then I thought I was not happy of where I am because I was in the wrong age group so now I decided that I would move out so at the moment I moved back at my parents and now there another flatting opportunity funny enough it's my friends house which is awesome as and she got the same group of friends that I got which is awesome so I move in next week and I am so excited my dream was is for me to flat with friends and now my dream has came true. So now I am going to focus on me being a tidy and clean person and to think about my budget and to keep going on my weight lost and to try to improve on my personal hygiene as well. And i want to be able to cook healthier options in house to. And I also want to do my chores without moaning.

I first met Andrew and Caroline as their teacher at the beginning of the 2008 academic year. They were two of the students in the transition class I taught within a special school in Christchurch, New Zealand. They were both 18 years old and have the label Down syndrome. Both had been educated for part of their schooling within a secondary school, and both had moved to Christchurch with their families. Andrew had come from the North Island and Caroline had come from the United Kingdom.

Terminology in the thesis

There is continuing debate surrounding terminology in the field of learning disability, with arguably no less stigma and negative connotations attached to those terms used in education and society now than previously. Categories by their nature are open to abuse and misinterpretation, reflecting particular social ideals and conditions. I have used the term learning disability) in this thesis because it is a term used by the People First self-advocacy movement in New Zealand, which Andrew and Caroline both became members of. However, use of direct quotes preserves the speaker's preferred usage. I refer to the participants in this thesis as "students with learning disability" to denote those still enrolled in secondary school and "young adults with learning disability" to denote those who have left secondary school or formal education. When I use the term "young people with learning disability," I refer collectively to both groups.

Importantly, students with learning disability are a heterogeneous group. With this in mind, the group of young people with learning disability our study considers are mostly those in schools identified by the Ongoing Resourcing Scheme (ORS) as high needs. As a comparison, in the United Kingdom these young people would be mostly labelled as severe learning difficulties.

The purpose of this thesis

The purpose of this thesis is to understand how students labelled with learning disability can make a successful transition from school towards the kind of life they want. The transition process from school is challenging within a neoliberal education environment that privileges those students who are expected to become financially, economically and socially

independent (Nairn et al. 2012). What I have learnt from the collaborative journey with Andrew, Caroline and the young people resists “expert” knowledge traditions, generalisations and assumptions concerning particular identities (Van Hove et al., 2009; Ware, 2006)).

The process of transition is examined in relation to learning disability, educational policy and practice through the narratives, experiences and perspectives of the students and young people living it. Young people’s voices are critical to disability research and endeavour (Ballard, 2007; Bray & Mirfin-Veitch, 2003; Slee, 2003). Actively and meaningfully involving young people with learning disability in the research process as co-researchers opens up new ways of thinking and new understandings about the social construction of learning disability. The young people are valued in this study as capable, purposeful and insightful.

Through an inclusive research process that promotes the positive recognition of our relative interdependency while acknowledging and attending to our individual uniqueness, we can find spaces where all people can be recognised for who they are and what they offer. I hope this research challenges policymakers, professionals and others working with students with learning disability during the transition from school to critically reflect on their policies, practices and values. This critical reflection should provide a lever for change, in which schools become places that ensure all students are welcomed and supported to make a successful move towards the kind of life they aspire to. Schools are heavily influenced by the related education policies and legislation of that country’s government and New Zealand is no different.

New Zealand’s policy and legislative context

Regarding policy in the United Kingdom context, Thomas and Loxley (2001, p. 99) make this argument: “Policy is not ... the virtuous outcome of some consensual democratic process. Rather it is the outcome of struggle and contestation, of a continually shifting political process, which not only decides what ideas are permissible, but who should articulate them.” Inclusive education policy and related documents convey particular expectations of education professionals, but that does not necessarily mean they are then embedded in practice. Although key documents, policies and legislation reflect and promote

inclusion, teachers and other educational professionals more often than not respond with deficit “special education” explanations and approaches (Ballard, 2003; Macartney, 2009).

The policy and legislative environment in New Zealand in recent years has developed inclusive ideals that one might expect to support the rights of students with disability in practice (Gordon & Morton, 2008). However, Gordon and Morton (2008) and Rutherford (2009) contend that education policies in New Zealand create confused and inconsistent messages regarding inclusive education for professionals, parents and students. Disability researchers Ballard (2007), Higgins, MacArthur and Morton (2008), Higgins, MacArthur and Rietveld (2006) and Macartney (2009) believe that New Zealand Ministry of Education policy documents often make statements that promote inclusion while at the same time using the language and practices of special education. This can be seen, for example, in the way references to “inclusion” and statements in support of special schools and special units within regular schools appear simultaneously in policy documents. In Chapter 6, I use the research participants’ voices to examine and critique New Zealand education policy work related to inclusive education and the transition process, as they explain how it acts in practice to position and exclude them.

By contrast, in other government departments there have been some moves to challenge the construction of disability as an individual and private deficit. The Ministry of Health has led this work through its New Zealand Disability Strategy (NZDS). The NZDS was developed through a consultation process with people from the disability sector, and the accompanying report (Minister for Disability Issues, 2001) received widespread support. The focus in defining “disability” within the NZDS is on the role of society in creating and maintaining barriers to the full inclusion and participation of people with disability. The NZDS aligns itself with the social model:

Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have. Our society is built in a way that assumes that we can all move quickly from one side of the road to the other; that we can all see signs, read directions, hear announcements, reach buttons, have the strength to open heavy doors and have stable moods and perceptions. (Minister for Disability Issues, 2001, p. 3)

As with all government departments, the Ministry of Education are required to report annually on their progress towards meeting the goals of the NZDS. The NZDS report (Minister for Disability Issues, 2001, p.1) states that “New Zealand will be inclusive when people with impairments can say they live in a society that highly values our lives and continually enhances our full participation.” However, since its inception, the NZDS and its potential influence on education structures, policy and practice do not appear to have been taken very seriously by successive governments, in particular by their Ministries of Education (Higgins et al., 2008; Higgins et al., 2006).

Whether all this inclusive policy and legislative environment has positively influenced the lives of the research participants in practice is an important idea in this thesis. I will argue regarding this policy environment that the quality, type and effectiveness of relationships between government departments has considerable influence on the success, or not, of the transition process for young people with learning disability – particularly in regard to the form, quality and continuity of support offered to students with learning disability transitioning from school.

Special education in New Zealand

Schooling is compulsory for students in New Zealand from 6 to 16 years of age. All children and young people are legally entitled to attend the local state school of their choice (New Zealand Education Act, 1989). Children and young people with learning disability can attend regular or special schools. The students in our study attended either a day special school or a regular school – with the majority attending a special school – and are labelled as students with special education needs. Each regular school receives general and targeted special education funding, depending on the decile rating of the school and the particular students attending. Special education funding is provided to individual schools to employ teacher assistant staff and other resources. Special education services and personnel such as therapists and specialist teachers mostly work in an itinerant manner with individual schools and students.

Students attending a day special school do so after being assessed according to Ministry of Education criteria under the Ongoing Resourcing Scheme (ORS) as having either “high” or

“very high” special education needs. The majority of participants received support under the ORS high needs scheme. ORS funding is used to pay for part-time teacher hours to support the classroom teacher, teacher aide hours, additional resources or equipment and the involvement of a special education provider and therapists. ORS-funded students represent approximately 1% of the total school population, and special schools work with a wide range of children who have been accepted into the ORS scheme. Meanwhile, many regular secondary schools have what are often termed “satellite” or “special” units for labelled students.

Transition for students with learning disability: “A restrictive pathway”

Reliable data on the transition to post-school outcomes for students with learning disability in New Zealand does not exist. Importantly, there is little specific data on the lives of people with learning disability in New Zealand, as they are usually included within the generic group of people with disability. However, in a consideration of the transition process from school (explored in depth in Chapter 2) there are some comments that can be made. The majority of students with learning disability leave school in New Zealand with no formal qualifications. They have extremely limited tertiary or paid employment opportunities, mostly attend vocational service day centres, have limited social networks and will live at home or in residential services long-term (Bray, 2003; Mirfin-Veitch, 2003; Bennie, 2005; Cleland et al., 2008; Cleland & Smith, 2011). In comparison to their peers without disability, most students with learning disability will be welfare dependent for life (Ministry of Health, 2010; Statistics New Zealand, 2008).

Keeping the lack of relevant data in mind, the following points provide a very brief snapshot of different aspects of life for young people with learning disability as a context for a holistic consideration of their lives.

Post-secondary education

Post-secondary education for young people with learning disability is well established in many Western countries, particularly the United States and United Kingdom (Grigal & Hart, 2010). In these countries, there is a growing expectation that young people with learning

disability should attend college or university after secondary school (Uditsky & Hughson, 2012). This is in line with the advantages, both social and economic, that further and higher education can offer a pathway to employment and a greater sense of belonging in society, as indicated in the Convention on the Rights of Persons with Disabilities (United Nations, 2006). This is not the case in New Zealand. As Grigal & Hart (2010) point out, expectations held by all stakeholders involved in the transition process impact heavily upon whether pathways into college are realised for young people with disability.

Employment

There is little valid data on employment outcomes for young people with learning disability in New Zealand (Bray, 2003; Mirfin-Veitch, 2003; Bennie, 2005), although Bennie (2005) and Cleland and Smith (2010) found that people with learning disability were less likely to be employed than any other disability group in New Zealand. The Ministry of Education does not keep statistics on post-school destinations for students with learning disability. Nevertheless, using statistical analysis from the LSTS in Christchurch, and through many conversations with fellow professionals in schools and services across New Zealand, I can draw some tentative conclusions.

School leaver statistics for ORS funded students gathered by the LSTS over three academic years – 2009, 2010 and 2011 – from eight secondary and special schools in Christchurch found that not one student went into full-time paid employment post school. Only 1 out of 68 ORS funded students over those three years gained post-school paid employment beyond five hours per week (that being 15 hours per week in a fast food outlet). Three went into short-term paid employment of less than five hours per week that lasted 6 months as a training scheme specifically for people with disability. 12 went on to a discrete further education course and 52 went directly into a vocational service day centre. Out of the 68 ORS funded-students, 49 were funded under the high classification and 19 as very high. The participants in our study were mostly funded under the high ORS scheme category. The vast majority of these students would be labelled as having an intellectual/cognitive impairment.

By any measure, it is clear that paid employment beyond a few hours is extremely unlikely for these young people, as indicated by New Zealand researchers Bray (2003), Bennie (2005),

Cleland and Smith (2010) and Mirfin-Veitch (2003). In addition, anecdotal evidence suggests that for the relative few who did further education and training, this did very little to enhance their employment prospects. On course completion, most either went into a vocational service day centre or ended up back in the family home most of the week, with little activity in the community.

Health

International research has consistently identified people with learning disability as experiencing poorer health outcomes than the general population. This is also the case in New Zealand (Webb & Rogers, 1999). In response to this inequality, Special Olympics International developed the Healthy Athletes Screening (HAS) programme, which offers targeted health screening at designated Special Olympics events. An analysis of the resulting health-related data by the Donald Beasley Institute in New Zealand identified specific health issues in the visual, auditory, oral and podiatry health status and health needs of Special Olympic athletes.

Living

Living in the community and participating in “everyday things in everyday places” has become the policy direction for disability services supporting people with learning disability in New Zealand (Enabling Good Lives Report, 2011). The support required to live in the community during the day is mostly defined by “placement” in a vocational service day centre funded by the Ministry of Social Development (MSD). In addition the Needs Assessment and Service Coordination (NASC) agency administers funds on behalf of the Ministry of Health for other supports for which young people are deemed eligible. In regard to housing, the majority of young people with learning disability will live with their family of origin for considerably longer than young people without disability.

Family and friends

Young people have been shown to spend the significant majority of their time in the company of other people with learning disability and family members (Hall & Hewson, 2006; Lippold

& Burns, 2009). This inevitably means they will have limited social networks. Families play a central role in the lives of young people with learning disability (Hornby, 2012) and generally do so for much longer than for young people without disability.

In the next section, I locate the research within Disability Studies in Education, a movement with a diverse membership who are nonetheless fully supportive of emancipatory and transformative agendas related to people with disability. I draw much of value from its promotion of the lived experience of disability, its critical stance against “expert” systems of knowledge and its challenge to educational exclusion at all levels.

Locating the research: A Disability Studies in Education framework

Our research study is located within the field of Disability Studies (DS), specifically Disability Studies in Education (DSE). DSE promotes people with disability knowledge and emphasises their perspectives in understanding the lived experiences of those identified as having a “disability” or “impairment” (Connor, Gabel, Gallagher, & Morton, 2008; Goodley, 2001). Through a focus on the individual narratives of people with disability, DSE members acknowledge the unique difference of all people with disability (Goodley, 2001). In order to expose and resist “expert” systems of knowledge, we must embrace the diversity of narratives people with disability offer (Slee, 2001b; Ware, 2005). In this thesis, the lived experiences and narratives of the author, two co-researchers and participants are imperative to developing a critical understanding and response to dominant and exclusionary discourses (Gabel, 2005; Maynes, Pierce, & Laslett, 2008).

Crucially, I position DSE as a moral, ethical and relational endeavour. It involves an international network and community of people with disability, practitioner researchers, students, scholars, teachers, family members and activists who seek to include, listen and respond to the voices of people with disability, challenging inequalities and supporting people with disability to find a sense of belonging in education and society (Connor et al. 2008; Gabel, 2005). Slee (1997) describes DSE as “a project in cultural politics” (p. 407). Gabel (2005, p. 9) puts forward this view of DSE research:

Research is concerned with a Freirian form of praxis, or a conscious effort at social change that brings about equity, social justice, and full participation in

society where the work toward social change is led by those who are themselves, oppressed.

DSE began as a special interest group of the American Educational Research Association (AERA) in 1999 (Gabel, 2005, p. 1). The DSE movement is founded on an emancipatory conceptual framework that has its origins in the “social model of disability” (Abberley, 1987; Barnes, Mercer, & Shakespeare, 1999; Gabel, 2005; Oliver, 1990, 1996). The social model of disability was developed in the 1970s and 1980s by British disability activists and sociologists as a reaction against traditional medical, biological and individualistic understandings of disability (Connor et al., 2008). It has been critiqued, expanded and reinterpreted over recent years. The basic argument of the social model is that disability is a social construction, and people with disability are discriminated against on the basis of biomedical, deficit constructions of disability. This idea remains central to disability activism and studies and provides a mandate for DSE members (Connor et al., 2008; Gabel, 2005; Goodley, 2001).

DSE members are critical of culturally and historically based notions of disability as “deviant” or “deficit” based on an ideal set of norms (Gabel, 2005; Ware, 2005, 2006). DSE covers a range of disciplines (Connor et al. 2008; Ware, 2006) and encourages conversations among individuals and groups representing and using different tools and perspectives in their analysis of disability and difference (Millar & Morton, 2007; Ware, 2005, 2006). Interdisciplinary conversations, coupled with the representation of multiple perspectives on disability, exclusion and inclusion, expand the complexity and diversity of the experiences of people with disability (Allan, 2008; Ware, 2005). I draw from DSE’s critical and emancipatory foundations and use it to examine and challenge special education ideologies and practices.

Critical inquiry

DSE critically explores, exposes and challenges how knowledge and power act to create inclusionary and exclusionary outcomes (Graham & Slee, 2008; Connor et al., 2008; Gabel, 2005; Smith, Gallagher, Owen, & Skrtic, 2009). This critical focus explores traditional

critical theories in education as to how categories of difference such as disability, ethnicity, gender, class and sexuality are conceptualised (Ferri, 2006; Ware, 2005). Ferri (2006) contrasts DSE's critical theorising with traditional special education understandings of disability and difference. Ferri criticises special education methods because they focus on aspects of identity and experience that are individualistic. Ferri suggests that special education does this to exaggerate differences between groups of students and fails to question how this normative construction is created (2006, p. 293). Special education's claim to objectivity and neutrality is thus challenged by the fact that minority cultures and groups are over-represented (Connor, 2008; Slee, 1997). The over-representation of minority cultures in special education is a manifestation of relations of power.

The fact that many academics, educators and practitioners outside of DSE do not consider disability to be an experience of oppression is based on the dominant belief that disability is a biological condition (Ferri, 2006). Linton (1998, p. 36–37) argues that in research outside of Disability Studies,

disabled people have existed predominantly as marginal figures, their contributions and perspectives are not generally noted ... The most fundamental problem ... is that disabled people's voices are almost completely absent from this picture, and so the understanding of disabled people's place in these situations is filtered through the experience of people who have never been in that place.

This provides a further mandate to challenge traditional views concerning who has the authority and right to represent and respond to disability in education and society (Ware, 2006). I can never speak for the young people with learning disability in this study, but I have a moral, ethical and professional duty to support them in the telling of their stories, "speaking" and learning from and with them. Relationships between people with and people without disability are crucial in DSE, as it is through this moral, relational, collaborative journey that we can co-construct narratives that challenge dominant discourses on disability.

Professional knowledge and control

Slee (1997, p. 408) suggests that we must consider who is producing theory and for what purposes. He asks the question, "To what ends are theories manufactured and deployed?" He

also asks, “In whose interests do particular forms of knowledge operate?” (Slee, 2001b, p. 171). These are important questions in this thesis, and they are at the heart of concerns with politics, culture and power in education and society.

Slee (2001b) and other DSE researchers (Danforth, Taff, & Ferguson, 2006; Skrtic, 1995) contend that the special education industry has developed and grown around medical and deficit notions of disability. Skrtic (1991) and Slee (1997, 2001b) argue that special education consciously and subconsciously perpetuates its position in order to insulate itself from democratic and human rights groups who challenge its role. There are also suggestions that both special education and the regular school system benefit from the physical and conceptual segregation of students with and without disability/special educational needs (Danforth et al., 2006; Slee, 2001a).

Retaining students with learning disability within a special education setting, with its perceived “expert” knowledge, continues the dominant social order in secondary schooling. Special education then becomes a conservative reaction to the increasing heterogeneity of school populations as it seeks to retain the status quo (Danforth et al., 2006). Slee (1997, p. 407) described the movement of “problem” students and populations from the regular school system into special education as one of “theoretical and political deflection.” Special education, coupled with mainstream education’s resistance to inclusion and diversity, has resulted in the continuation of an “unreconstructed school system” (Slee, 1997, p. 4). For Slee, an inclusive view of education becomes a means to realise educational and human ends, and not a realisation in itself.

Principles of inclusive schooling suggest that the expert professional is not automatically a co-worker in the project of change and that they need encouragement to enlist new skills and knowledge to render their expertise consistent with the goals of new forms of democratised schooling. (Slee, 2001a, p. 393)

The special education teacher is often seen by the secondary school teacher as the “expert.” This is unsurprising given that most secondary school subject teachers have been immersed in a Western psychology-based knowledge paradigm in their teacher education programmes (Skrtic, 1991, 1995; Slee, 2003). Morton and Gibson (2003) suggested in their conference paper that professional expertise legitimises the expert’s hegemonic role and can create

relations of domination. This means the secondary school subject teacher often defers to the special education teacher as the “expert” on students with learning disability and will seek their expertise and uncritically follow their advice in how they position, value and work with students with disability (Brantlinger, 2006; Slee, 1997).

In the American context, Skrtic views the rise of special education as “the failure of the public education system to educate its youth for full political, economic and cultural participation in [a] democracy” (1991, p. 24). This has relevance for New Zealand and other Western countries in highlighting how the history of public education can link disability with other social categories of difference such as race, class and gender, resulting in the dilemma of democratic ideology in schools on the one hand and the reality of class structure on the other. This dilemma was required to justify unequal social divisions of labour in capitalist economies and the rise of special education classes in the late twentieth century. Erevelles (2005, 2011) saw this as providing the impetus for disability to become prominent in education discourses. The continuing exclusion of students with disability in education over recent years is seen by Erevelles to result in schools being increasingly responsible for maintaining a surplus of young people to be allocated low paid, low status work and/or those deemed unable to work and reliant on the welfare state. These ideas have relevance for young people with learning disability as reliant on the welfare state. These ideas are explored in this thesis.

The glue that binds this research is the critical aspect that it takes from DSE. This research challenges and rejects deficit, individualist notions of learning disability and seeks conceptual frameworks and interpretations that are relational and respond positively to differing contexts (Gabel, 2005). DSE has provided a challenge for my professional and personal thinking and practice that has shaken the very foundations of who I am as a teacher and special educator. DSE and special schools would appear to represent counter-positions. I rationalise this apparent contradiction in my work as a special educator by exploring methods that can encourage mainstream and special school professionals to utilise their individual expertises collaboratively towards the kind of schools that embrace all students. Educational transformation can only be realised when all teachers recognise that they are agents of inclusive teaching and learning. I combine the notions of teacher and practitioner researcher

at the point where likeminded practitioners come together to enact change from within, in direct support of and collaboration with those who are excluded and marginalised.

In the next section, I describe the literature on exclusion, inclusion and special education in order to outline some of the key education issues and ideas that this thesis tackles in its search to understand how students and young people with learning disability can transition successfully from school towards a good life. These issues have a direct bearing on how students with learning disability experience the process of transition.

Exclusion, inclusion and special education

The aim of these next sections is to define the terms exclusion, inclusion and special education, their interrelationship and their relevance to this thesis. The terms are inextricably linked. They have influence over each other, defining and acting to position many of the social, cultural and political discourses playing out in New Zealand education and in relation to the transition process. Exclusion is a key construct in this thesis, utilised to position, explore and understand the lives of the students and young people with learning disability within education and society. In this section, I define the term more broadly as “social exclusion,” using the critical social thought of Paulo Freire. I then move on to sketch out how exclusion, inclusion and special education are related within education. I utilise the work of Freire again, for his liberatory and emancipatory stance; I also draw on Slee for his educational critique and call for more democratic forms of education. In addition, I draw on others within and beyond the field of DSE. The influence of neoliberalism on education and society is also addressed, particularly its pervasive influence on education in New Zealand today.

Exclusion

Exclusion is a complex, multi-faceted concept used in and across a range of disciplines. It can be utilised in different ways for different purposes to mean different things. The term “social exclusion” originated in France and replaced terms associated with marginalisation and poverty. Peace (2001) describes social exclusion in this way:

Social exclusion could be imported into New Zealand as one concept among many. It could sit alongside the more familiar concepts of “poverty,” “being underprivileged,” “experiencing hardship,” and seeking to attain a “good quality of life.” Thus, rather than providing a new framework that introduces unanticipated consequences, social exclusion becomes another conceptual tool for talking about the *linked and cumulative factors* and processes that confound individual and group capacity for hope, opportunity, reciprocity and participation. Social exclusion (and social inclusion) becomes further “ways of naming” the collective processes that work to deprive people of access to opportunities and means, material or otherwise, to achieve well-being and security in the terms that are important to them. (pp. 33–34)

Peace presents some useful themes that I will draw on for this thesis: words like “hope,” “opportunity,” “reciprocity” and “participation.” I will extend his use of “participation” to a “sense of belonging” and will draw on these ideas and themes as the thesis unfolds. Peace’s definition also seems to imply that you cannot consider exclusion without discussing inclusion at the same time. Exclusion is implicit to ideology, culture and technologies of power. Exclusion is pertinent to the individual as well as groups and can heavily influence any person’s journey towards a good life. Exclusion is a term which is flexible and somewhat amorphous in use, yet there are core features which separate it out from previous notions such as poverty or marginalisation. Social exclusion can involve economic, political and spatial exclusion as well as lack of access to specific areas such as information, medical provision, housing, policing and security and so on. These elements are interrelated and involve exclusion from what are seen as the “normal” areas of participation of full citizenship (Percy-Smith, 2000). Importantly, social exclusion is a social rather than individual problem.

The work of Freire (1996) is useful to highlight an exclusionary society as a divided society, which is characterised by “the oppressor-oppressed contradiction” (p. 31). The consequence of this contradiction is the dehumanisation of both the oppressed and the oppressor. Freire connects dehumanisation to passiveness. In the relationship between oppressor and oppressed, prescription becomes evident where the behaviour of the oppressed is a prescribed behaviour that follows the guidelines of the oppressor (p. 28–29). In this process, Freire states, “the oppressor ... is himself dehumanised because he dehumanises others” (p. 29). To exclude the other is always and at the same time to exclude the self. Hence, Freire writes of the oppressors’ “monopoly on having more as a privilege which dehumanises others and

themselves” (p. 41). Echoing Fromm, he states that they “no longer *are*; they merely *have*” (p. 42). I now consider what exclusion means in education.

Exclusion in education

According to Freire (1996), an education that focuses on the individual and seeks to alter the disaffected, the excluded and the marginalised is morally wrong. What is needed is an education that tackles the causes of disaffection, exclusion and marginalisation. To this end Freire says:

For the oppressors ... it is always the oppressed (whom they obviously never call “the oppressed” but — depending on whether they are fellow countrymen or not — “those people” or “the blind and envious masses” or “savages” or “natives” or “subversives”) who are disaffected, who are “violent,” “barbaric,” “wicked,” or “ferocious” when they react to the violence of the oppressors. (p. 38)

Freire goes on to suggest that a deficiency view of the oppressed acts as a distraction – a way of diverting attention from the dehumanising contradiction which polarises persons and making the many others the problem and therefore excluded.

Roger Slee has written extensively on educational issues related to exclusion. In his view, “there is nothing more undemocratic than a language that excludes, especially when an inaccessible language masks a paucity of thought” (2011, p. viii). I draw heavily on his insights to anchor my ideas and argument. In relation to education and disability, Slee (2006) links the concept of exclusion to an individualised and technical view of both disability and education. This individualised and technical view can be seen in a range of perspectives. As with Freire, one is an individualised view of disability; another is a narrow view of what education success is; and a third is the “expert” in special education. All these perspectives then have the consequence of denying diversity and the unique difference of the individual, and they therefore have relevance for students with learning disability.

The effects of exclusion from education can be seen through a lack of a sense of belonging (Osterman, 2000), the devaluation of people (Booth, 1996) and limited employment and citizenship (UNESCO, 2005). This thesis is an examination of the process of exclusion and inclusion in the transition process. Within education and the transition to post-school life

there are a number of elements that influence being excluded or included. These elements are the students, parents, the leadership of schools, professionals and paraprofessionals, initial and continuing teacher training, the physical environment, curricula, policy and many others. The interplay between these elements can have a profound impact on a student with learning disability and their transition, acting to position them as strangers in both school and the wider society. These multiple elements and stakeholders in the transition process, and the relationship between them, define a complex and often competing range of issues and tensions that arise for the student with learning disability (Dee, 2006). An important idea in this thesis is the quality and effectiveness of the relationship between these stakeholders and the relationship between inclusive education policy and practice.

Market models, competition and exclusion in education

If we accept the notion that disability is a personal tragedy (Fulcher, 1989) rather than a social concern, we will never tackle issues of exclusion within education, policy and society. Exclusion is evidenced in the marketisation and performatisation of schools, seen through prescriptive curricula, competition among schools, national standards, league tables and performance-related pay for teachers. Exclusion is also articulated through the language of choice for schools as they make choices about which students will, and conversely will not, bring them up the league table (Slee, 2000). In New Zealand, the self-management of schools introduced in 1989 has arguably made schools more individualised and exclusionary through adhering to the market model and competitive environment (Ballard, 1999). Slee summarises this market proposition as whether students add value or risk to the school when he says that “successfully playing the market means that some students are a poor investment” (Slee, 2001a, p. 392). This idea has much relevance to this thesis in its influence on post-school outcomes for students with learning disability.

Slee (1998, p. 446) sees school curricula as being at the heart of educational exclusion and cites the National Curriculum in the United Kingdom as an example. The New Zealand curriculum (2007b) has challenges regarding its relevance for students working long-term at or below level 1. Parents will often choose schools they perceive have and will maintain high standards, where competition is the mode of selection. This leads to a narrow view of

educational success and how it is judged, which has also been cited by Slee as promoting exclusion:

Inspection of schools' performances against each other through the largely franchised inspectorial force overseen by Ofsted also militates against diversity as schools strive to secure common cultural form and academic benchmarks ... The linking of funding of teacher training to inspection performances is sufficient inducement for conformity. (Slee, 1998, p. 448)

Arguably, this competitive environment – with its inherent problems for students with learning disability – is evident in the current New Zealand government's drive to ensure that standards in schools are audited and reported by its Education Review Office (ERO).

Slee (2000) asked an important question of the audience at the 2000 International Special Education Conference (ISEC) at the University of Manchester: "Have we allowed ourselves to be enlisted to support the collateral damage of league tables, inspection regimes and inappropriate curriculum for the twenty-first century and beyond?" For Slee, solutions to the systemic and structural barriers surrounding the exclusion of some students must emanate from democratic, creative and transformative action that follows much of Freire's vision and problematises the very functions and foundations of education in contemporary society (Slee, 2000). In his keynote speech at ISEC, Slee (2000) described how the diversity of human beings is reduced and simplified in that "multidimensional human beings are reduced to their mono-dimensional signifiers." Solutions within education must acknowledge and indeed celebrate change, so that difference and diversity are embraced as recognising the uniqueness of all students rather than their sameness. Slee sees this shift occurring in the requirement for new social technologies that challenge exclusion on a democratic basis, where social justice, rights and equity are at the fore. Like Slee, I draw on Bauman's notion of "the stranger" through this thesis to position young people with learning disability in education and society.

Special education and exclusion

Inclusion and exclusion in education is not only about location or setting. Slee (2000), again in his keynote speech at ISEC, provides an important critical definition of special education by drawing on the work of other key researchers in the field:

The commonsense of special education represents a set of discursive practices (Foucault, 1974) founded upon unequal power relations that favour professionals pursuing good works for their needy clients. Moreover, the traditional special educational commonsense draws its legitimacy from an interdisciplinary bricolage that is based upon so-called scientific assumptions about individual pathological defectiveness that eschews the politics of disablement. Whatever disciplinary apparel you dress it in, it still amounts to a form of what Jenny Corbett (1996) has described as “badmouthing.” Many of my colleagues including Sally Tomlinson, Len Barton, Mike Oliver, Jenny Corbett and Tony Booth in the United Kingdom and Tom Skrtic, Linda Ware, Doug Biklen, Dorothy Kerzner Lipsky, Alan Gartner, and Ellen Brantlinger in the United States have contributed to the foundation and elaboration of a sociology of special education that presents options for conceptualising and responding to educational exclusion and inclusion.

For Slee, special education is concerned with technist assimilation, where defective students are made to fit the schooling (Slee, 2001b, p. 170). To match the increasing number of students with special education needs, the special education system has naturally expanded to meet the ever-increasing demand.

Special education has been challenged on a range of levels. Skrtic (1991), writing in the American context, defined it as “the profession that emerged in 20th century America to contain the failure of public education to educate its youth for political, economic and cultural participation in democracy” (p. 24). In the New Zealand context, Ballard (2003) has been equally critical when he says that “special education exists to cater for children who are deemed sufficiently different that they do not belong within ordinary school settings alongside others from their community” (p. 6). Special education, while existing to cater for the perceived failure of secondary education, can be also viewed in part as masking the mutually beneficial relationship that exists where both act in each other’s best interests. Special education benefited from supporting secondary education through taking its “problem” students, which in turn allowed for students without disability to avoid being distracted (Barton, 2000).

New Zealand’s Ministry of Education has often been challenged for their policy work that aligns “inclusion” with the language and practices of “special education” (Higgins, MacArthur, & Morton, 2008; Higgins, MacArthur, & Rietveld, 2006; Kearney, 2009;

Ministry of Education, 2010). This is evidenced in Ministry of Education policies and official documents that combine references to inclusion with statements that support the retention of special schools, and special classrooms or units within secondary schools (Higgins et al., 2008). The Ministry of Education uses neoliberal arguments and rhetoric to justify support and funding for separate schooling options for students with learning disability and others with disability (Higgins et al., 2008; Higgins et al., 2006; Kearney, 2012). The foundations of neoliberalism are constructed on the beliefs that education is an individual good, where individuals act as “rational” and autonomous individuals, and that students as consumers have equal educational opportunities and choices (Ballard, 2004; Gordon & Morton, 2008; Slee, 2010). I believe that this will always present challenges for young people with learning disability, who require some form of support and are perceived to have limited agency. More importantly, the neoliberal belief that all students act as autonomous consumers and have equal educational opportunities is a myth when set against the reality that secondary-age students with learning disability are marginalised and excluded on any social marker.

This thesis is not a direct criticism of special education and its professionals, as I am a special education teacher. Indeed, I have seen “inclusive practice” within a special education setting. This is not about bad special education but about how schools can be places where all students feel welcome and belong. I explore new ways of thinking about exclusion, inclusion and special education. Slee challenges us in this way when he calls for new voices and new ways:

Hitherto the voice of the professional expert has prevailed in the field of special education. The voices of teachers, educational psychologists, special educators, educational administrators and bureaucrats, together with medical practitioners, a range of therapists and traditional special educational academics have formed an ensemble of voices, the end product we see in the forms of exclusion and inclusion in our schools today. Changing this requires new voices working from a new score. (Slee, 2000)

This thesis tells the story of an attempt at a transformative response to the challenge that Slee, Freire and others from within DSE provide for all professionals working with students labelled with special educational needs. A research agenda where a practitioner researcher

comes together with two young people labelled as “special” explores solutions to educational exclusion through such a new score.

I now turn my attention to what the literature says concerning inclusion and education, exploring those ideas that will best support students with learning disability in their search for educational equity and opportunity.

Inclusion and education

Slee (2001a) suggests that inclusion in education is primarily concerned with all students and democracy when he says that “inclusive schooling requires new knowledge and analytic tools to consider the articulation of identity and difference in new forms of schooling” (p. 381). Slee views inclusive education as fundamentally about the kind of schools that support the inclusion of all students. Allan (2005) concurs when she suggests that inclusive education is not a project to be done on a “discrete population of children, but rather (as) something we must do to ourselves” (p. 293). For Slee (2011), research within inclusive education “should be to build robust and comprehensive analyses of exclusion in order that we might challenge social and cultural relations as mediated through education in order to dismantle oppression and promote inclusion” (p. 83).

Recognising the significance of inclusive education begins, for Slee, in a discussion about how inclusion in schools has been understood. Slee (2001a) argues that “the rhetorical commitment of education authorities and teachers’ industrial associations to inclusive schooling remains for many conditional and chimerical” (p. 385). He asserts that inclusive education must differ from special education. Slee (2001b, p. 171) argues that inclusive education must be critical, unlike “special education which remains uncritical of its pathological gaze and continues to reduce social issues to personal troubles.” He goes on to claim that “special education stumbles into the reductionist trap of promoting inclusive education according to the technical assimilationist imperative of making ‘defective’ kids fit the school as it is” (Slee, 2001b, p. 170).

Therefore, Slee believes that inclusive education pivots on the contentious issue of how to secure and maintain access to mainstream educational institutions for all students. He writes:

Our starting point ought not to be the question how do we move the special education sector into the mainstream of schooling school and thereby overcome exclusion? This is assimilation. More properly we ought to commence with an interrogation of the formation of regular and segregated schooling as a first step towards a different educational settlement, the inclusive or democratised school. (Slee, 2001a, p. 388)

In this sense, to move beyond assimilation, there is a requirement “to place the technical questions of placement, resources and the deployment of expertise into their second, nevertheless important, order place” (Slee, 2006, p. 118). For Slee, inclusive education is about all children and democracy, whereas special education is about individuals, meeting special education needs and bureaucratic rationality. He views inclusive teachers as resisting “marginalising discourses of normality and exceptionality” (Slee, 1998, p. 444).

Inclusive education towards democratic education

Kluth, Straut, and Biklen (2003) define inclusive education as something

that supports, impacts, and benefits all learners. We see inclusion as an educational orientation that embraces differences and values diversity. Further, we view inclusion as: a revolution, a social action, and a critical political movement. [All] students deserve to be educated in ways that make them struggle, think, work, and grow. (p. 3)

For Kluth et al., a sense of belonging, as a value and philosophy, is based on what Stainback, Stainback and Ayres (1996), like Slee, view as democracy in education. Slee (2001a, pp. 387) also calls for “inclusive schooling” to be located within “the more significant project of democratic schooling.” Slee makes the case for an inclusive understanding of inclusive education. Inclusive education is about all students. Inclusion is an aspiration for a democratic education and, as such, the project of inclusion addresses the experiences of all students at school (Slee, 2001b, p. 168).

Summary

Thus far, I have used the literature to describe the terms “exclusion,” “inclusion” and “special education” and present what they mean for this thesis. In doing so, I have hinted at key ideas

and debates within education and some of the causes of exclusion related to technist, individualised and “expert” policies, systems and bureaucracies. This provides a complex environment for young people with learning disability trying to transition from secondary education. An interest in this thesis is how special and mainstream education expertise can be utilised collaboratively to create inclusive and democratic education environments where all students transition successfully.

I understand that barriers to inclusion and successful transitions can be found in the tensions between neoliberalist market models, which drive education policies founded on competition and prescriptive understandings of success, set against a call for more democratic forms of education. This appears to encapsulate contemporary debates on exclusion, inclusion and special education. I now turn my attention to the effects of neoliberalism and its implications for students with learning disability. I do so because neoliberalism has been pervasive across most Western countries, particularly New Zealand, influencing government economic, social and, importantly, education policy. This has impacted on students with learning disability and their transition from school.

The influence of neoliberalism

Contemporary Western societies like New Zealand have been greatly influenced by neoliberalism. The lives of young people with learning disability have consequently been influenced, in largely negative ways. Neoliberalism is defined by some as a theory of political economy where individuals are best served “by liberating individual entrepreneurial freedoms and skills within an institutional framework characterised by strong private property rights, free markets, and free trade” (Harvey, 2005, p. 2). However, in another context, neoliberalism can be seen as giving rise to what has been called the “moral underclass” discourse (Levitas, 1996), which positions the socially excluded as culturally distinct from mainstream society. From this position, neoliberalism becomes about behaviour rather than how society is structured and its inequalities. These are observations across most Western liberal democracies, including the United States, United Kingdom, Australia and New Zealand. The social impact of these policies differs from country to country but, I argue, is profound.

For Farnsworth & Holden, neoliberal doctrine promotes a market dominated by multinational corporations that are driven to control public life by maximising their profit (2006). If we examine this doctrine with regard to understandings of education, community, inclusion, belonging, interdependency and support, and the journey towards a good life, there are clear implications for students with learning disability. Neoliberalism reframes society and its constituents, including government, from a “socially caring” standpoint to one of “look after number one” or the “autonomous individual.” Independence is celebrated and dependence is rejected. Interdependency is enacted through competition. Under these new rationalities, the social becomes reconfigured as a series of quasi-markets. Dean (1999) considers this situation as one in which “services and expertise are provided by an array of publicly funded, non-profit and private for profit organisations which are placed under the surveillance of regulatory authorities in order to normalise, stabilise and optimise activities, identities and power relations” (p. 174).

The global financial crisis of 2007 appeared to present a fundamental challenge to neoliberalism as the body of ideas that have constituted the political orthodoxy of most “advanced” economies – including New Zealand – in recent decades. Colin Crouch (2011) argued in his book *The Strange Non-death of Neo-liberalism* that neoliberalism would shrug off the challenge because while it seems to be about free markets, in practice it is concerned with the dominance over public life of the giant corporation. I view neoliberalism as ultimately about power and its influence, which is another key idea in this thesis. This has been intensified, not checked, by the recent financial crisis and general acceptance that certain financial corporations are “too big to fail.” Although much political debate remains preoccupied with conflicts between the market and the state, the impact of the corporations on both these areas is today far more important (Crouch, 2011). In this light, it could be argued that New Zealand is a corporation and John Key its CEO, with the resulting negative educational, social and economic forecast for its most vulnerable and marginalised people.

Current political policies within western economies are prioritised around saving money, promoting profit and efficiency. This market economy doctrine has pervaded the welfare state, producing a type of quasi-market relationship between diverse political players such as government departments, service professionals and the recipients of their support. Young people with learning disability had marginal political, social and economic participation prior

to this neoliberal drive, and these developments have served only to further question whether students and young people with learning disability can have any meaningful control over their lives. Self-determination for these young people becomes concerned primarily with who controls the definition (Smith & Routel, 2010), implying disciplinary regimes of bureaucratic and professional control that are operationalised through government policy service systems and processes and their professionals.

Young people with learning disability remain at the whim of these service gatekeepers, who allocate support, resources and funding according to criteria that has no real connection with them. I suggest this positions them, to use Bauman's (1991, 1997) metaphor, as *strangers* to regular education and the wider community, operating in a form of parallel system and place. Bauman conceptualises the stranger in terms of the social other, where it polices the boundaries between self and other. I utilise Bauman's sociology of the stranger to position students with learning disability in what he describes as the transience of today's liquid-modern society.

People with learning disability have been subjected to a long iterative process in history where they have been defined and redefined to produce a complex, multi-layered construction governed by ever-changing, globalised, economic and political conditions. I view the rise of neoliberalism as an important political philosophy in Western democracies, and it has had a profound impact on the way education and human services respond to learning disability.

The education and social management of people with learning disability – through the historical shift across many Western countries from deinstitutionalisation to new forms of government policy and service provision, based on conscious or unconscious frameworks like quality of life (QoL), normalisation, social role valorisation (SRV) and individualised or personalised services – still frames these people as something to be solved by service systems, professional expertise and charitable models. The rhetoric of human rights, justice and citizenship has largely been forgotten in the melee surrounding government policy that supports those who assess needs and administer funds (Davis, 2000).

Slee views neoliberalism as a social imaginary where competitive individualism trumps community and interdependence (2011). I now consider neoliberalism and its influence on education in New Zealand.

Neoliberalism and New Zealand education

Neoliberalism is pertinent to this study because of its heavy influence on contemporary education and social welfare systems, services and their professionals, other personnel and the recipients of their endeavours. Neoliberal political and economic doctrine has infiltrated education and social welfare systems with its “let the market decide” proposition, and I argue that it is implicated in creating exclusionary forces for the young people in this study. To form education into the market model has required policies of corporate management and competitive practice (Ballard, 2004, p. 98). The implication of bringing the market into the education and social welfare spheres raises questions concerning whether these young people, their families and allies can positively influence the course of their journey towards a good life.

Changing conceptualisations of social justice for young people with learning disability are reflected in the emergence of policy rhetoric with words like “choice,” “participation,” “community” and “empowerment” in education and society. This is true of the education and social welfare system in New Zealand (Ballard, 2004, 2007; Gordon & Morton, 2008) and other Western economies (Slee, 2000, 2006; Newell, 2005). It is evident that the policy rhetoric is aimed at producing normalised, competent, capable and independent citizens. Education and social welfare services in New Zealand are still committed to goals that stress the importance of social and behavioural competence. The result is the continuing power of the professional voice in how these services are designed, delivered and, importantly, evaluated. This professional paradigm is embedded in social policy and practice in New Zealand. Contemporary social schemas like QoL and SRV still influence service policy and practice today, objectifying students and young people with learning disability as passive recipients of education and social welfare support in a way that results in restrictive pathways and unrealised lives.

Neoliberal ideology, practices and structures in New Zealand over the past two or three decades have seen financial and administrative responsibilities for New Zealand schools devolve to local community concerns (Gordon & Morton, 2008). A 1989 government initiative saw the establishment of individual school Boards of Trustees (BOTs), mostly comprised of parents and staff. The establishment of school BOTs reduced the government's role, responsibilities and direct relationship with schools (Higgins et al., 2006). Since this policy implementation, New Zealand schools have largely been self-governing, and they compete with each other within an education marketplace (Gordon & Morton, 2008). This delegation of school management to families and teachers has distanced the government and their agencies from the decisions schools make and their practices in relation to students with disability (IHC, 2008; Slee, 2003).

As far back as 1996, the Ministry of Education (1996, p. 1) stated its intention to create “a world class inclusive education system.” This sentiment has been repeated recently in the government's *Success for All – Every School, Every Child* document (Ministry of Education, 2010). However, Higgins et al. (2008) suggest that the New Zealand education system is moving away from, rather than closer to, this lofty claim:

A growing body of evidence that New Zealand's neoliberal paradigms (with their emphasis on the individual and on education as a private commodity), and mixed messages about education for disabled children, have limited the country's progression towards an inclusive education approach, where the focus is on quality for all children. (p. 146)

Higgins et al. (2008) describes this situation as evidence of the government reverting to old policies that move away from inclusive education. The Ministry of Education's working definition of inclusion appears to be directed at learners who are labelled as having special education needs, rather than transforming the system in ways that will enhance the inclusion of all learners (Ministry of Education, 2010). I now outline some of the taken for granted assumptions regarding people with learning disability.

Assumptions concerning young people with learning disability

This section will briefly describe some of the assumptions regarding how young people with learning disability may experience life. On a personal level, they may be perceived to lack the

communication skills to express their views. On a cultural level, negative discourses of disability may influence the way that other people relate to them. On a structural level, they may have access to limited capital and may experience prejudice due to their gender, race, religion or sexual identity.

Society holds many overarching judgements and values about people with learning disability. Firstly, difference is not always seen as something that is positive, and secondly, the lives of young people with learning disability are often devalued by the concept of the “eternal child.” The belief in these concepts may lead society to think that young people with learning disability do not have the right to speak or to be listened to. Instead, they are believed to require protection. Young people with learning disability may also find it difficult to engage in rationality. It is likely that they will have a difficulty with communication which may hinder them in expressing their views or persuading others to take an alternative standpoint. As contemporary society places such high value on further education, training and employment, this acts to differentiate them from the dominant group. Additionally, to maintain or progress one’s social position, one needs to acquire more social capital. Young people with learning disability often will not have the opportunities to acquire more social capital or may not have the knowledge or the right support to maximise their social position. Repeated exposure to negative comments can also affect one’s ability to engage in rationality through the development of “learned helplessness.”

Summary

What I have attempted to illustrate thus far is a complex and contradictory landscape where relationships at the macro and micro level in education and society are all too often founded on power, individualism, perceived capability and competition. This landscape places young people with learning disability in a precarious position. My interest is in understanding what the young people with learning disability at the receiving end of all this endeavour feel about it and how their lived experiences can provide insights and support better relationships, from the policy level through to practice in schools. What do these young people consider important as they make the transition from school? What are the factors that support or hinder it from their perspective, and not what others have said on their behalf?

From my examination of literature related to exclusion, inclusion and special education, professional discourses appear to signpost early on in the student's transition that their pathway might already be mapped out. I test this idea through the findings chapters in this thesis. I have highlighted DSE members' calls for a more collaborative, democratic and human response to the perceived problem of young people with learning disability in education and society. I now introduce and consider the concept of a good life as a way of framing and understanding the lived experiences of young people with learning disability. The belief that anchors my argument is that relationships are fundamental to finding solutions for how we can all journey towards a good life. By getting relationships right at all levels and in all ways, we can collectively make that journey. This thesis describes that journey.

The search for a good life

A good life is one that emerges from within the person and as a result of their experiences which are linked to their evolving values and inner worlds. (Johnson & Walmsley with Wolfe, 2010, p. 173)

I now turn my attention to a key idea and construct for this thesis, "the search for a good life." I do so because it allows me to conceptualise life generally, as well as what it means for young people with learning disability and the different elements they consider important. It also encourages me to explore, understand and interpret the lived experiences of the young people with learning disability in this study in ways that are different to more traditional forms of meaning. Historically, a good life for young people with learning disability has been provided largely by other people. These people have mostly been professional people representing education and social welfare services, and they have usually assumed the voice of authority. It is important to acknowledge that we are inextricably linked through our histories and the narratives of our journey towards a good life.

It is accepted that different cultures and communities have different interpretations of a good life. If government and its policy has not explicitly defined what it means by a good life, then it follows that there will be different interpretations. When governments take a "one size fits all" approach, this will naturally create problems for those who do not fit that size. Johnson and Walmsley with Wolfe (2010) explored what a good life might mean for people with

learning disability from a British perspective, and I draw on their work in this section as it partly looks outside of disability studies to the disciplines of Western philosophy and psychology. Like them, I acknowledge that utilising “Eurocentric” ideas is restrictive; there is much to learn from other cultural considerations, particularly – in the New Zealand context – indigenous Maori and also Pacifica peoples. However, disability and related policy in New Zealand is still very much driven by Western cultural influences and neoliberalism (Nairn et al., 2012).

The great philosophers of Western civilisation, such as Aristotle, Plato and Socrates, spent a great deal of time and effort on the meaning of a good life. Thoughtfulness and critical self-awareness were the foundations for their philosophy. They viewed the good life as inextricably linked to the inner life, the life of the inquiring mind. This has historically created tensions in relation to people with learning disability, as assumptions concerning their capacity for this form of reasoning have been led by psycho-medical discourses that want to quantify their capacities and capabilities (Johnson, Walmsley with Wolfe, 2010).

Over the last two decades, there has been a great deal of discussion about what makes a good life for people with learning disability. Much of it is based on the work of people like Dr Robert Schalock and his quality of life measures, looking at what qualities are in a good life for everyone and then extrapolating from this to the lives of people with disability – often with a quantitative emphasis (Johnson & Walmsley with Wolfe, 2010). Language plays an important part in these discourses. In the New Zealand context, the Ministry of Health’s current disability policy work – for example, in publications like the *New Model of Supporting Disabled People* (2012) and *Enabling Good Lives* (2011) – uses the language of “a good life.” This has considerable implications for the young people in this study, as they have much to gain and lose by its implementation. The excerpt below is taken from the IHC website:

Like all New Zealanders, people with an intellectual disability have the right to a good life; to live, work, play and contribute to their local community. They have a right to have their say and make decisions. Sometimes additional supports are needed so that this can happen. People with an intellectual disability have the right to good support so they can have a good life.

IHC retrieved at: <http://www.ihc.org.nz/campaigns/community> on 05/10/12

The right to effective support is critical for the young people in this study and points to a potentially fruitful change of emphasis in policy work from an “ordinary” to a “good” life. The recognition of natural supports rather than only service support being provided is another idea explored in this thesis.

Johnson and Walmsley with Wolfe (2010) discuss a range of elements that may contribute towards a good life, including pleasure, duty/virtue, happiness and the balance between freedom and constraint. Pleasure and happiness are seen as mostly momentary, episodic and contingent on other factors, particularly our values, purpose and commitment to others and how they provide direction in our lives. Students with learning disability are nearly always considered to be under the duty and care of others, as seen in their contemporary social and education management (further described in Chapter 2). I recognise the close connection between virtue and pleasure that allows for values that the young people hold to be acknowledged as part of their inner life. This inner life and the recognition of our interdependency is what emerges in Chapter 7.

Contemporary New Zealand society, as with the majority of Western societies around the world, is caught up in what Bauman (2008) calls “the pursuit of happiness,” but this is at best elusive and momentary. Happiness that is tied to economic growth, consumerism, competition and individualism is problematic; in Bauman’s view, it results in the loss of a sense of duty to each other as human beings and the breakdown of community. Bauman (2000, 2008 & 2011) views the individual pursuit of happiness as a dominant discourse in Western capitalist societies. In addition, the focus on growing affluence in these societies does not necessarily equate to increased happiness, and so I believe the search for a good life must focus elsewhere.

In relation to affluence, the growing gap between the rich and poor and the ever increasing pace of that gap defines many Western countries’ challenges today (Rashbrooke, 2013). Rampant consumerism and the search for momentary happiness are largely witnessed by young people with learning disability from the margins of this contemporary pursuit, since they are restricted to being primarily welfare consumers (Statistics, 2008) and socially isolated through limited social networks (Chappell, 1994; Hall & Hewson, 2006; Mason, Timms, Hayburn, & Watters, 2013; Reinders, 2002). Being happy is often cited by supporters

and family of young people with learning disability as all they want for their son or daughter. The government view of happiness can be viewed as how individuals can contribute to theirs and the country's material wealth. However, Johnson and Walmsley with Wolfe (2010) point out that perhaps we need to consider the less concrete aspects of life (p. 57). It may be that living away from home and having paid work is a realistic goal for many of the young people in this study. However, if this means living alone, isolated and not having the financial means to interact meaningfully with other people, then it might not be so desirable. I contend that a good life for people with learning disability often focuses on other people's interpretation of it, while their own experiences are explored only at the surface level without truly finding out what they see as a good life. I consider that happiness is not something that necessarily takes a prime position in the journey towards a good life. It is not a goal, but something that may come along the way through a sense of fulfilment. It comes and goes, and it manifests itself in different ways to different people. Contentment, purpose, value and a sense of belonging are more useful elements to focus on in our search for a good life. In addition, if we are to live with others, then we need to balance freedom with constraint – otherwise the risk of chaos is all too obvious, as demonstrated by the constant conflicts across the globe.

Young people with learning disability have historically been perceived as unable to make reasoned or good choices, and as therefore requiring some form of support or constraint through management or control. This is partly related to age and experience, but also emerges in deficit discourses surrounding people with learning disability. Johnson and Walmsley with Wolfe (2010) elaborate:

When reason is impugned people may find themselves excluded not only from a good life, but also from any consideration by others that they are able to reflect or to develop an internal life of values, beliefs, hopes and dreams. (p. 5)

People with learning disability often carry with them a stigma of flawed reasoning and a lack of capacity for abstract thought. People with learning disability then become an identified group whose life may only improve through being controlled and managed over a long period of time. This view has influenced the lives of people with learning disability, for instance in relation to IQ testing and eugenics (Johnson & Tait, 2003). If, as Western philosophers would say, a good life comes from within, through reflection and values that lead to wisdom, then young people with learning disability's inner lives are often left unacknowledged and

unrecognised. This can lead to a focus by families and support workers on pleasure and happiness, all too often encapsulated in material possessions, independence and autonomy (Johnson & Walmsley with Wolfe, 2010, p. 53). I suggest a move away from the conflation of intelligence with reason. Intelligence is seen in Gardner's (1990) view as multiple, and in Nussbaum's (2001) interpretation in our emotions and passions. There must be recognition of external factors, but we should at the same time explore the inner factors that will lead to deeper mutual understanding. To understand the lived experiences of young people with learning disability, I must endeavour to "live" with them through the research process and beyond.

Bauman (2008) and Giddens (1991) put forward the view that life is momentary – a series of phases or episodes that we create – and changes over time as our dreams, goals and aspirations evolve. Johnson and Walmsley with Wolfe (2010) highlight the difficulty this implies for defining a good life for people with learning disability (p. 48). This thesis seeks to understand what kind of life young people with learning disability want as they transition to post-school life and how this knowledge can inform their and our search for a good life. This requires fundamental questions to be asked. What does it mean to live a good life? Or, as Bauman would ask, what is the art of life? What are the fundamental elements that comprise a good life? This thesis is an exploration of such questions through a collaborative, relational and reciprocal journey.

In regard to a good life, does equality matter? Not everyone is equal, but inequality matters because it can refer to equality of justice and rights, equality of opportunity, equality of access, equality of outcomes and so on. I position equality as related to ethics and social justice in society. Reducing inequality is a goal for New Zealand, but in terms of income inequality, the gap between the rich and poor in New Zealand is growing at a faster rate than any comparable society (New Zealand Treasury, 2011). Reducing inequality in education, employment and healthcare can allow a person to benefit from their rights as citizens and to actively belong as full members of society. I view the road to equality as a complex journey that society and its members must continually move forward on together. At the same time, I would say there is no perfectly just society – but as the Nobel laureate Amartya Sen (2009) advocates, we should attempt to remove inequalities that are unjustified.

My consideration of what a good life means frames a critical examination of the life that students with learning disability have experienced, experience now and might experience in the future, particularly with respect to how that journey unfolds as they transition to post-school life. I argue there is a contradiction between the contemporary Western understanding that a good life is equated to competitive individualism and the fact that all of us will require some form of support in our lives. If, as I have suggested, relationships are crucial in our search for a good life, then we need to consider what that means. In the next section I introduce the “relational dimension” as a key theme that runs through and binds this thesis.

The relational dimension

Solutions for how the young people in our study can transition from school to a good life are to be found in the recognition that relationships play a central role in all our lives. Relationships are fundamental to human life. The interactions we have with our fellow humans will profoundly influence the type of life we live. We live our lives through interdependency. As outlined in Chapter 2, on transition at the macro level, the relational dimension is concerned with relationships at the policy level and how that translates into practice in schools. At the micro level, it is the relationships that are developed between among schools, other stakeholder organisations and individuals involved as students, parents, professionals, support workers and members of the wider community.

At the macro level

An underlying tension in the debate concerning exclusion, inclusion and special education is how they are inextricably related to each other, creating tensions and dilemmas in regard to the transition to post-school life for students with learning disability. As discussed earlier in this chapter, relations of power and control come to the fore where special education policy and bureaucracy acts to maintain an “expert” status over its relationship with students with learning disability. I argue that policy and practice related to transition is defined by its lack of clarity, conflicting policy messages for students and parents, poor planning, difficulties with inter-agency collaboration and the inflexible and restrictive pathways created as a result. Effective relationships then become essential in seeking solutions for how students with learning disability can journey towards a good life as judged by the young people.

At the micro level

At the micro level, the relationship between students with learning disability, their families and the array of stakeholders charged with supporting their transition is defined by a disjointed process that mostly starts too late, is not student or family-centred and lacks effective collaboration (Bray, 2003; Mirfin-Veitch, 2003; Cleland et al., 2008). I suggest that these factors act to create the expectation that these young people should transition into vocational day services post-secondary education. Effective person-centred transition planning has been emphasised as the key to successfully moving into the next stage of life for young people with learning disability. However, achieving success involves more than a single technical solution, such as good planning. Rather, it is concerned with a complex array of interrelated factors. These include attitudes and expectations at the individual and institutional levels, including schools, their staff and others involved from support agencies.

Conclusion

In this chapter, I have introduced my co-researchers and provided ideas about what this thesis will entail, as a collaborative journey that seeks understanding through, in many ways, “bottom up” theorising (Allan & Slee, 2008). I have situated the study within DSE to develop the argument that answers to learning disability and how young people with learning disability can transition from school towards a good life are to be found in ethical, social, political, cultural and relational understandings and interpretations. I have sketched some of the key debates, issues and understandings around exclusion, inclusion, special education and neoliberalism. I have hinted at the influence of market ideology, which I take up in later chapters. I have suggested the New Zealand Ministry of Education continues to articulate conflicting messages about inclusive education. These messages do little to prioritise or support the development of inclusive or whole-school approaches in education. They help to maintain confusion about what inclusion means and hinder the journey towards inclusive education (Higgins et al., 2008).

Crucially, this thesis seeks to provide a platform for the narratives of young people with learning disability and find real, meaningful and practical ways to support them in their

journey towards a good life. This means that relationships must play an important part at all levels. I have suggested that relationships between policy and practice related to inclusion, exclusion and special education has been confused and contradictory. There has also been an assumption that the relationships between stakeholders in the transition process are what might be described as “power neutral.” This is not the case, which is the result of a competing and complex range of interests that are described through my thesis. I believe these complexities have left school leaders and teachers without a clear understanding and direction of what is expected of them in developing inclusive educational environments. I will argue that one of the consequences of this is a lack of whole-school approach to the transition process for students with learning disability.

Outline of thesis chapters

In Chapter 2 I explore the literature related to the transition from school and some of the issues and tensions for education policy and practice. I consider why transition planning is important for all students with and without disability and what is considered best practice. I also hint at the separation of mainstream and special education transition processes and the utility of a career. I then move on to examine contemporary social responses to learning disability providing a recent history of how these young people have been understood in society and some of the reasons why.

In Chapter 3, I describe the theoretical framework that I have drawn from in my interpretation and analysis of the research data. I examine the ways in which social constructionist and interpretivist epistemologies and theories are relevant to a consideration of how learning disability is understood and experienced. I develop a rationale for theory that promotes an interpretative, critical, reflexive approach and draws from a range of perspectives to explore and examine the social construction of disability and the lived experiences of young people with learning disability as they transition from school. I introduce the social thought of Zygmunt Bauman and in particular his use of metaphor and its relevance in positioning the experiences of young people with learning disability.

In Chapter 4 I describe in detail the methodology and methods adopted for our study. I discuss and justify the methodological approaches I have used in the research and some of the

issues raised by these in terms of their relevance to the research questions and the theoretical perspectives outlined in Chapter 3.

Chapters 5, 6 and 7 are the findings chapters and present and interpret selected data from the focus groups and other sources related specifically to the research team including verbatim excerpts from co-researcher journals, conference and other presentations, text messages and email communications. Also transcriptions of research team meetings. Chapter 5 presents what kind of life the young people with learning disability wanted and what they got. In Chapter 6 I use data to explore education policy and practice related to transition to highlight the exclusionary landscape for students with learning disability. I present some of the factors that create exclusion for these young people from educational opportunity and its effects. Importantly, I relate the findings in Chapters 5 and 6 to relevant literature within the field to move my argument forward through the findings chapters. Chapter 7 is dedicated to the findings from the journey of the research team as an alternative to the exclusionary landscape that leads to unrealised lives presented from data in Chapters 5 and 6.

In Chapter 8 I address the research questions presented at the end of Chapter 3. I suggest that answers to how young people with learning disability can transition successfully from school are all about relationships. I provide a framework that I call the 'relational dimension' to position the elements that are important to consider in any person's search for a good life. Through the relational dimension I discuss the substantive research findings and their implications for young people with learning disability.

CHAPTER 2: TRANSITION, LEARNING DISABILITY AND SOCIETY

Introduction

In this chapter, I explore the literature around transition as it relates to both students with learning disability and those without disability, to signal that these groups largely experience different transition processes. I then move on to examine contemporary social responses to learning disability. This literature review will lay a foundation for the findings and discussion chapters, while building on the theme begun in Chapter 1 of the exclusionary processes that influence the experiences of young people with learning disability.

I first explore the theory, policy and practice of transition and explain how it relates to students with learning disability as they make the difficult move from school to post-school life. I then provide an overview of recent contemporary social approaches to the “problem” of learning disability to provide a historical context for the management and control of people with learning disability. This relates to the contemporary education issues described in the section on exclusion, inclusion and special education in Chapter 1.

I begin with a definition and overview of what the term “transition” means for this thesis, then I review how transition is conceptualised and positioned within education theory, policy and practice. I make brief reference to policy and practice within the wider social and welfare landscape, in recognition of the fact that this thesis is concerned with the transition from an educational environment to a community environment. I draw on transition to post-school life as a process for all students, in order to highlight the gap between students with and without learning disability. Further, I utilise recent literature on theory, policy and practice from the United States, United Kingdom and New Zealand to provide a comparison and context for how the process of transition from school plays out in the lives of students with learning disability and their families as they move through their secondary schooling and enter the adult world. I conclude by drawing on current best practice in New Zealand as former manager of the Lead School Transition Service in Christchurch.

Conceptualising transition

The Oxford Dictionary defines transition as “the process or a period of changing from one state or condition to another” (OED, 2013). This general definition has relevance, as it describes transition as a process and not an event (McGinty & Fish, 1992). This definition also recognises that transition is a period of change. *Transition: Getting It Right for Young People* (United Kingdom Department of Health/Child Health and Maternity Services Branch, 2006) also provides a useful definition of transition:

Transitions occur throughout life and are faced by all young people as they progress, from childhood through puberty and adolescence to adulthood; from immaturity to maturity and from dependence to independence. In addition, some young people experience extra transitions as a result of other life events for example, bereavement, separation of parents, and being placed in care. (Accessed online 28/09/12 at <http://www.intellectualdisability.info/life-stages/transition-for-children-with-intellectual-disabilities>)

However, what seems clear about transition from recent literature is that as a construct in contemporary Western societies, it is no longer a linear process where one moves from one stage to another in a predictable manner (Dee, 2006; Higgins, 2002; Mitchell, 1999). Nairn et al. (2012) suggest the duality between transitions – as a construct for change on the one hand, and as a steady progression through predictable stages from child to youth to adult on the other – is problematic. It is problematic for any young person, and we need to question whether it is still appropriate in 21st-century Western societies. However, whether this linearity and predictability still remains relevant for young people with learning disability in its most restricted sense becomes an important idea in this thesis. Referring to young people in general, Higgins (2002) comments:

The international literature makes clear that young people encounter transition as a multi-faceted, non-linear process deeply embedded in institutional and social relationships and practices. In the post-war years in NZ, however, transitions policies simply transferred segregation among pupils into segregation among workers, while in the 1980s and 1990s the purity of the model of transition employed in policy assumed away a network of complexities that young people encounter in their choice-making and experiences of transition. (p. 57)

As researchers suggest, the non-linear nature of the transition process in most contemporary Western countries defines the context for the majority of young people. This begets the question of how students with learning disability experience the transition to post-school life in this complex environment. The move from “dependence to independence” is an important phrase and is contentious in relation to young people with learning disability. Historically; people with learning disability have been seen as dependent on others in various ways and to varying degrees. Special education and social welfare systems, services and their professionals have been responsible for managing that perceived dependency in schools and the community, as described in Chapter 1. This management is explored in second half of this chapter in relation to contemporary social responses to people with learning disability. What is clear from the literature is that the word “transition” is a term that has been used by professionals, particularly in relation to young people with learning disability leaving school, for approximately 25 years (Dee, 2006; Smith & Routel, 2010); in New Zealand, however, it is a term used only in the last decade or so.

In recognising transition as a process, it is fair to assume that all the transitions we make in our lives are interconnected. However, the transition process specific to this thesis is that from school to post-school life, and it is theorised in different ways by different people. Statistics New Zealand (2008) describes this particular transition as an ongoing and cooperative process in supporting a student to move from school to the next stage in life. It is this next stage that has proved such a challenge for students with learning disability who, I will argue, have been largely excluded from many of the opportunities experienced by their peers without disability, such as further education, paid employment, house rental or ownership, developing diverse friendship networks, marriage and children.

Research has shown that the transition from school is a major life change for any young person and their family (Dee, 2006; Nairn et al., 2012). However, the context in which students with learning disability and their families experience this transition is complex, as they negotiate meanings within unequal power relations, structures and systems such as education, health and social services, medical and other professional stakeholders (Barrkman, 2002; Raymond, 2002; Bogdan & Taylor, 1998; Seymour, 2001). For young people with learning disability, it is a time fraught with competing tensions and dilemmas (Ball, Maguire, & Macrae, 2000). Cooley and Moeschler (1993) describe how we all experience many

transitions in our lives – like moving from childhood to adulthood, finding a partner, changing jobs and buying a house – as well as going through fundamental stages such as birth, puberty and death. Our lives, then, are full of transitions and changes; further, how we rise or fall to these challenges and, crucially, how we interact with others and are supported to meet them will influence the types of lives we will lead. How we respond, individually and collectively, and the form of support we receive during the journey, becomes crucial and will have a direct bearing on our search for a good life.

Transition models

Mirfin-Veitch (2003), a New Zealand researcher, suggests that there are a number of different ways of theorising the transition to adulthood for people with learning disability, but according to the literature they fall mainly into two areas: “life phases” and “institutional status.” Meanwhile, Certo et al. (2008) highlight three institutional transitions: school to work, housing and domestic. How students with learning disability are prepared at school for this transition to post-school life becomes of paramount importance to the student and family. Preparation implies planning, which becomes a key element in the transition process and is discussed in detail later in this chapter.

Dee (2006) “explores the process of transition from three different but complimentary perspectives described as phase-related, agency-related and time-related” (p. 5). I now briefly describe these.

The phase-related model

The phase-related model of transition identifies a number of stages that we all go through in reaching adulthood. The Centre for Educational Research and Innovation (CERI) in the United Kingdom adopted this approach in 1986 as a way of defining a student’s secondary education as the first part of “a continuous journey that starts well before pupils leave school and does not end when they first enter work” (p. 42). Dee (2006) describes several markers of adulthood: paid employment; personal autonomy with legal and civil rights; friendships and social activities; and family roles and responsibilities. She acknowledges the real challenges

that students with disability experience in achieving adult status, such as negative attitudes and assumptions, a lack of information and a shifting labour market.

The agency-related model

Dee (2006) uses the agency-related model to define “the degree of agency and control that an individual has in determining the course of their lives” (p. 5). She acknowledges that while family, socio-economic status, gender and ethnicity continue to have a significant impact on people’s lives, the majority of people are more willing to challenge society’s taken-for-granted expectations of its citizens. The Western neoliberal drive for the “autonomous individual” has arguably brought about empowerment, control, greater mobility and self-determination for some, yet greater challenges for others including young people with learning disability.

The time-related model

Dee (2006) uses the time-related model to describe a process of lifelong development that has derived from many schools of thought, including biology, socio-psychology and sociology (p. 6). Dee draws on the work of Merriam (1999), who identifies three dimensions of time, that impact on the development of adulthood: historical, life and social time. Time has influenced societies and cultures in relation to changing expectations. Young people stay in education much longer in Western countries, but this might not be the case in other countries with different cultures (Browder et al., 2001). Dee points out that “different cultures emphasise different degrees of relatedness which varies not only between cultures but between ethnic minorities within the same society” (p. 7). Rites of passage are important and lead to one achieving different milestones that provide a purpose and value in life. For young people with learning disability, these rites to adulthood are often not experienced, experienced to a lesser degree, or experienced in a different way. Transition for young people with learning disability and their families is also largely played out through public bureaucratic processes (Ball et al., 2000). This does not always reinforce the positive aspects of these important milestones being reached and serves only to reinforce the young person and their family’s failure, anxiety and fear about change and what the future brings.

Other models

Other attempts to conceptualise school to post-school transition processes for students with disability were made in America by the Office of Special Education and Rehabilitative Services (OSERS) (Will, 1984). This model placed employment as the primary outcome of the transition process. Halpern (1985) proposed a model where community living was viewed as the primary outcome. Both of these models were based on special education services in American high schools.

A widely accepted and utilised model for transition practice is Kohler's (1996) taxonomy for transition programming. The model is suggested to improve post-school outcomes for students with disability. It informed what Kohler and Field (2003) referred to as "transition-focused education," which they described as being

...directed toward adult outcomes and consists of academic, career, and extracurricular instruction and activities, delivered through a variety of instructional and transition approaches and services, depending on the local context and students' learning and support needs ... [It] represents a shift from disability-focused, deficit-driven programs to an education and service-delivery approach based on abilities, options, and self-determination. (p. 176)

The methodology used to construct the model was based on concept mapping and positive student outcomes. The taxonomy comprises five categories: student-focused planning; student development; inter-agency and interdisciplinary collaboration; family involvement; and program structure and attributes. The model reflects many of the key tenets of best practice from the literature and its emphasis on the importance of relationships is pertinent. However, it is nevertheless based on principles of normalisation and individualisation, where the skills and services required for leading a "normal" lifestyle are attained by an individualised approach to planning and service delivery.

So far, I have defined transition as a process that implies a change from one stage, phase or state to another, which all humans go through in life. I have suggested that the transition from school to post-school life is a complex and difficult one for anyone and is no longer a linear path for those without disability. As described in Chapter 1, bureaucratic processes and control by special education services complicate this process for students with learning

disability, and this greatly influences their post-school choices, decision-making capacity and pathways. Decision-making for students with learning disability is often in the control of others, particularly professionals, and implies issues of status and power (Dee, 2006; Riddell, Brown, & Duffield, 1994; Smart, 2004). I have implicated special education knowledge and control as heavily influencing the transition process for students with learning disability.

I have briefly defined some different models from the literature and some ideas about the inherent tensions and challenges for students with learning disability. Transition as a move from where one is now to the next phase or stage in one's life is time-related and indicates a pathway to be taken. The notion of a pathway, and questions of whether there is one pathway or many pathways and whether they are open to young people with learning disability in the same way as for others, becomes an important idea in this thesis. I have introduced some ideas related to notions of dependence and independence, the degree of agency, relationships and work that are seen as important elements in the transition process and are taken up as the thesis unfolds. In particular, the quality and type of relationships developed during the transition process will have an important influence on the young person's outcomes post school. Different research studies by Beadle-Brown (2006), Heslop and Abbott (2009) and Dyson, Meagher and Robson (2002) all found that students with learning disability were not meaningfully involved in the process of deciding what to do with their lives, even though many had clear ideas about it. This begets the questions of whether students generally are meaningfully involved in, and what importance schools place on, good transition processes and practices.

Why transition is important in New Zealand education

There is a large body of research related to transition in the context of students and young people with disability. Much of this research and literature attends generically to people with disability but does not refer specifically to those with learning disability. Hornby and Witte (2008), in a follow-up study on post-school outcomes, found that the transition process from school was an important aspect for students at the margins of the education system. It is evident from the literature that the transition from school to post-school life is a key period in any young person's life that education and schools play a crucial role in, yet one which these institutions do not always place enough emphasis or significance on. It is my belief that good

career and transition education should be a critical component for all students in supporting them to create a positive pathway towards a good life.

The majority of students in New Zealand transition from school to further education, training or employment. The move from school into further education and employment was found by a recent major research programme in New Zealand to be a complex process for all young people, and especially so for those at the margins of the education system (Nairn et al., 2012). New Zealand has suffered from high youth unemployment for a number of years now. The Organisation for Economic Co-operation and Development (OECD) figures for September 2011 showed 19.4% of young New Zealanders aged between 15 and 24 years were unemployed. The OECD Ministerial Council, who met in May 2013, produced an *Action Plan for Youth – Giving Youth a Better Start in the Labour Market* in response to the global financial crisis and structural barriers that are preventing many youth from making the transition from school to the labour market. The report stated:

Giving youth a better start in the labour market is not only vital for improving their well-being and fostering greater social cohesion but also for boosting potential growth and limiting future social expenditures, especially in the context of rapid population ageing in most countries. (p. 1)

Employment here is related to well-being and social cohesion. The report goes on to state that

action is needed both to bring immediate results in alleviating the current situation of high youth unemployment and underemployment and to produce better outcomes for youth in the longer run by equipping them with relevant skills for the future and removing barriers to their employment. (p. 1)

The action recommendations include better pathways from school, a higher level of education for youth and resolution of skill mismatches. Importantly, this OECD work showed that student failure needs to be tackled at policy, system and school levels. Schools are, by definition, well placed to support this process. After all, what are we educating our students for, if not to prepare them for their transition to post-school life?

Transition pathways

I now explore the common transition pathways for the majority of students without disability in New Zealand to emphasise the issues many young people have with transitioning from school. This, in turn, lends increased urgency to the fact that students with learning disability in New Zealand have very little access to these pathways into further education, training and employment that are deemed vital for all other young people.

Fluid pathways: Transition to tertiary education, training and employment in New Zealand

Higgins (2002) suggests that there is little useful data on transitions between school and further education, training and employment in New Zealand. Recent New Zealand government policy has encouraged young people to be in further education, training or employment after school (Ministry of Education, 2010; Nairn et al., 2012). However, there has been a significant and persistent percentage of these young people who have found this extremely difficult (Ministry of Education, 2010; OECD, 2013). In New Zealand, over 40% of students who enrol in tertiary study drop out before completing their qualification – giving New Zealand one of the highest drop-out rates in the OECD, second only to the United States (OECD, 2012). Student retention rates are poorest in polytechnics, with part of the reason for the gap being they have higher levels of part-timers and higher levels of students enrolled in what are deemed as lower-level qualifications.

A report by the Tertiary Education Committee (TEC), *Poutamatia: Youth Transitions between Secondary and Tertiary Study in New Zealand* (2011), explored pathways from secondary into tertiary education. Significantly, this report did not take into account students with learning disability, as they do not generally access tertiary education. Findings from the report point to the fluid New Zealand system (McKenzie, 2002) as an individually constructed model that offers a number of inexplicit channels through tertiary education and into employment, with young people and their families being expected to navigate these pathways themselves. The most significant government intervention in this system is financial, via state-funded education loans and tuition subsidies. The loosely coupled model of New Zealand and other similar countries like Australia have advantages in that they are

“flexible and responsive to changes in labour market demand, and are thought to provide the learner with a wider range of skills and aptitudes” (McKenzie, 2002, p. 207). However, this same system offers less certainty for young people, and can produce relatively large numbers of under-qualified and non-qualified youth who leave secondary and tertiary education for what often becomes long-term unemployment.

This is the situation currently in New Zealand, and it has certain important ramifications. The New Zealand system, influenced by neoliberal policy, largely places responsibility for choice of vocation and training on individuals, who are expected to identify the correct pathway according to their financial means, academic ability, and access to sound advice and information. In schools, sound advice and information has been usually provided by the careers department, with support from external agencies like Careers New Zealand. Access to good planning, support and information at the right time is clearly a serious issue for most students and their families, but for those at the lower rungs of the educational achievement ladder, it results in uninformed choices leading to unproductive and limiting pathways (Madjar, McKinley, Jensen & Van Der Merwe, 2009).

Whether students with learning disability are actively involved or largely excluded from this loosely coupled system becomes an important idea explored in this thesis, as what control students with learning disability and their families have over decision-making processes is a significant issue in transition planning for the future. As indicated in Chapter 1, students with learning disability are constrained by bureaucratic systems, processes and special education knowledge, attitudes and expectations during transition. In addition, unemployment rates in many OECD countries for the 16–25 age range are a worrying symptom of a complex range of social, economic, cultural and political issues in a technological, transient, globalised world. This provides a troubling backdrop for students with learning disability trying to make their way in a neoliberal, market-driven and depressed economic climate.

The global economic downturn of 2008–2009 has exacerbated the poverty and deprivation of tens of millions worldwide (McCord & Vandemoortele, 2009). An economic downturn imposes significant costs on individuals, with impacts transferred through shrinking employment opportunities; reduced wages; declining levels of demand; and cuts in government expenditure, especially with regard to basic social and welfare services. The

major long-lasting impacts of a crisis are most likely to affect young people and are likely to have long-term and often lifelong and even intergenerational consequences. The extent to which an economic crisis compounds these phenomena is a matter of major concern, as are the policy responses to crisis episodes (see, for instance, Harper, Jones & McKay, 2009). Statistics clearly demonstrate that in a global recession it will be the young people who are least qualified, skilled and experienced who will be the most vulnerable and excluded from the tertiary education and labour market. This provides a challenging environment for students with learning disability making the transition to post-school life.

Restrictive pathways: Transition to tertiary education, training and employment in New Zealand for students with learning disability

The very few recent studies of post-school outcomes for young people with learning disability have found they are less likely than young people with other forms of impairment to be engaged in school, work, or preparation for work in the years after leaving school (Newman, Wagner, Cameto & Knokey, 2009). Students with learning disability in New Zealand do not access university and have very limited, mostly discrete opportunities in polytechnics or training establishments (Cleland & Smith, 2010; O'Connor, Kubiak, Espiner, & O'Brien, 2012). Anecdotally, this barren landscape for tertiary opportunities is exasperated by the fact that the few discrete courses available nationwide for students with learning disability do little to provide pathways into tertiary and on to other study/training or paid employment. Because there is such a scarcity of tertiary courses for young people with learning disability post school, and available provision is mostly discrete within polytechnics or part-time courses at private tertiary providers, there is no meaningful data to make comparisons in New Zealand.

This restrictive landscape for students with learning disability in further education and training is repeated in relation to paid employment. There is little data on employment or unemployment rates for this specific group as they are again usually identified within a generic disability group (Statistics New Zealand, 2008). The few studies in New Zealand that consider employment and people with learning disability – by Bray (2003), Bennie (2006), Mirfin-Veitch (2003) and Cleland and Smith (2010) – describe a barren picture of extremely limited paid employment. If further education, training or employment post school is so

unusual for students with learning disability, we need to understand why and how it is perceived for students with learning disability in schools. In the next section, I explore what place the transition process has in New Zealand schools.

Positioning transition in New Zealand education and schools

Historically, “transition” as a term in New Zealand education has been associated with vocational rather than academic post-school routes, which might be considered the “poor cousin” to university study (Vaughn, 2003). Students not achieving academically undertook transition classes, which usually meant leaving school earlier to take up semi-skilled or unskilled work. However, in recent years, vocational and academic choices have been reinterpreted through the term “pathways.” Transition pathways imply complexity and therefore a range of possible options and directions, with all pathways perceived as valid. Modern apprenticeships are increasing in number, and well-established school transition programmes like Secondary Tertiary Alignment Resource (STAR) and Gateway are increasingly popular with students, schools and tertiary institutions (Vaughn, 2003). Current New Zealand education policy direction promotes the view that everyone should be on a pathway somewhere. That “somewhere,” as mentioned earlier, is generally assumed to include further education or training and employment. This form of deregulation in transition has encouraged closer relationships between schools and tertiary institutions as well as a plethora of courses, credits, options and choices in recent years. Young people are now seen as consumers and commodities in an education marketplace. Making good choices in this environment and therefore receiving effective guidance and support in order to navigate through this complex landscape becomes crucial. The word “career” makes an appearance at this stage in discourses about transition for students without disability. The word “career” implies that everyone is on a pathway. Students are then required to have a “career pathway” which will lead them towards their post-school goals. Career and transition education in schools is where this process plays out. The importance placed on transition by schools varies widely in New Zealand and was highlighted in the New Zealand Council for Educational Research (NZCER) *Survey of Careers Education in New Zealand* (2007) which reported patchy practice and a lack of coordination. Since 2007, there has been a good deal of work in the area of careers and transition.

Within the secondary school environment, it would be logical to draw the conclusion that transition is best positioned within the new Career, Information and Guidance Education (CIAGE) framework. For students in New Zealand schools, it is this new integrated careers and transition education approach that is responsible for providing the appropriate knowledge, advice and guidance in how to support and achieve their post-school goals (Careers New Zealand, 2011). As highlighted in previous sections, these post-school goals are framed, for the significant majority of students, with the expectation of leading to further education and or training that in turn leads to employment (Higgins, 2002; Nairn et al., 2010; Vaughn, 2007). When students with learning disability do not usually transition into further education, training or employment, there arises the important question of whether policymakers and career professionals consider them in this new framework.

Careers New Zealand and the Career and Transition Education Association (CATE) are the key government-funded organisations that drive and promote effective careers and transition practice for all students in schools. CATE's main focus is

on the career education of youth and their transition from school into the wider world of employment, training and/or further education. The majority of our members are school careers advisors, transition teachers and STAR, Gateway and Youth Apprenticeship coordinators. Other members work in associated areas, such as Career Services, tertiary training, local government, private business and industry training organisations. (CATE website accessed 24/07/13 at: <http://www.cate.co.nz>)

CATE's focus and emphasis, then, is on preparation for "the wider world of employment, training and/or further education." Other aspects of a student's life are not considered because of the expectation that they will manage it themselves.

Recently, the Ministry of Social Development (MSD) in the South Island of New Zealand has funded a youth transitions project that tracks school leavers to ascertain their status and bands them according to whether they are succeeding on their career pathway. The tracking service assesses whether the young people are in danger of not entering employment, further education or training (NEET). For those at risk, the tracking service then hands over to an appropriate youth support service, typically a youth worker, who works with the young person and family on a plan to engage or re-engage in employment, further education or

training. This tracking service does not include those who were classified at school under the ORS, which includes the majority of students in our study. Instead, students with learning disability are supported by an MSD transition contract, taken up overwhelmingly by vocational services running day centres. This has seen the majority of students with learning disability transitioning directly into a local vocational service day centre (Gladstone & Thomas, 2009). This situation raises a significant question concerning the expectations the education system and schools have for their students with learning disability: do these students require a career and transition planning if their pathway is already mapped out? Planning, then, becomes an important aspect of transition.

The importance of transition planning for students with learning disability

The majority of literature regarding transition planning has come from the United States. Transition planning is portrayed in the literature as an essential feature of the transition process (Riches, 1996; Winn & Hay, 2009). At this point, I do not distinguish between special schools and secondary schools in regard to transition planning. This is because in my professional experience in New Zealand, whether in a special or a secondary school environment, transition planning is overwhelmingly under the control of special education professionals. Ward, Heslop, Mallett and Simons (2003a) describe what transition planning should cover:

The transition plan is supposed to draw together information from a range of individuals, within and beyond the school, in order to plan coherently for the young person's transition to adult life in a holistic way, touching on every aspect of their future life, including living arrangements, personal and social life, well-being, education, training and work. (p. 133)

Importantly, this definition suggests planning takes a holistic view of the young person's life in drawing together key information from a range of people involved. The Council for Disabled Children in the United Kingdom provides the following definition of transition planning:

Effective transition planning is an important part of the transition process and planning can only be effective if a person-centred approach is taken. This means that the disabled young person is at the centre of the planning process, and that

plans are made based on the needs and aspirations of the young person. A multi-agency approach to transition supports person-centred approaches, as it means that all professionals are working together to support the young person.

(Accessed online at: www.transitioninfonetwork.org.uk 03/10/11)

The definition above provides some important elements for the transition planning process, particularly the requirement for a person-centred approach. This has been a real challenge for schools and associated professionals as it in many cases goes against more traditional pedagogical forms of practice, in particular the “expert” approach often adopted by special education. I suggest that although person-centred planning has been universally accepted as an integral part of the transition planning process in schools for students with learning disability across most OECD countries for over 20 years, it is not embedded in New Zealand secondary and special schools practice. One reason for this is that there is no generic transition planning process across schools or expectations about what effective planning looks like. The influence of neoliberalism in education has meant that schools have largely gone their own way, with guidance only from the Ministry of Education. During my role as manager of the LSTS, each school had their own transition planning process, mostly utilising the Individual Education Plan (IEP) process. This led to confusion between the IEP and transition planning processes. There is also confusion concerning who is responsible for the planning process in secondary schools and what it should actually contain and do. In addition, there are often many different plans held by different stakeholders in the process. The unifying element often missing in this confused service-orientated transition planning environment is the student-centred approach.

In terms of the decision-making process at play during transition, planning is of central importance. Transition planning is a multifaceted component of the education process. The student is reaching the age of maturity, while the family is dealing with the change in perception of their son or daughter from child to adult. Ryan, in his United Kingdom-based research *Values in Action* (1997), directly consulted young people with learning disability about their transition experiences, highlighting four characteristics required for transition planning to be useful for students and young people with learning disability. For Ryan, transition planning must:

- be empowering; have an emphasis on real work
- be flexible
- focus on all aspects of personal development
- facilitate the development of local services

Ryan's research essentially focuses on technical rather than relational aspects of transition planning. In addition, Thomas, Rogan and Baker (2001) describe a transition planning process that incorporates the development of a formalised, student-centred plan that focuses on employment; recreation; community living and participation; post-secondary education; and self-determination. Research in the United States on transition planning suggests student and family participation and student self-determination results in greater post-secondary education and employment rates and the achievement of positive post-school outcomes (Benz, Lindstrom, & Yovanoff, 2000; Wehmeyer & Palmer, 2003).

Barriers to effective transition planning for students with learning disability

In the American context, transition planning and models emerged in the 1980s and were not formalised until the 1990s (Neubert, 1997). A common problem is when professionals view transition planning as a programme instead of as a process (Riches, 1996). In New Zealand, "transition planning" has only been a term used in the last decade or so (Mirfin-Veitch, 2003); for students with special educational needs, the IEP has been viewed as the key tool for planning programmes, curricula and transition in schools. My experience working in and with schools leads me to believe that transition planning for students with learning disability has often suffered in New Zealand from being portrayed as an external service or agency responsibility, as with the MSD transition contract for ORS students, with the result that schools have not necessarily seen it as their responsibility to provide for those students who may require additional support. However, schools are well placed to take a lead role in ensuring students with learning disability are provided with effective transition planning. For many students with learning disability, schools and their staff are a constant over many years, and they therefore have the familiarity and knowledge to coordinate long-term, planned support. However, my professional experience has led me to believe that this is unusual in the

majority of schools. The best transitions provide a seamless movement of the student from school into the next stage in their lives (Test, 2008).

Armstrong and Davies (1995) conducted a study in the United Kingdom that focused on the experiences of 29 young people with learning disability leaving special education. The findings highlighted the different expectations that staff had for students with more severe learning disability compared to those with moderate learning disability in terms of achieving post-school employment goals. The study by Ryan (1997) found that professionals saw their role in transition planning as caught in the dilemma of students' chances of achieving their post-school goals, inhibited by a climate of limited opportunities and heavy competition.

Another important aspect of the transition planning process is the multi-agency approach, which ensures a collaborative process as the student's goals and support needs are put in place and that outcomes are sustainable post school. In my professional experience as manager of LSTS, effective multi-agency collaboration is unusual rather than the norm. There are many reasons for this: service-orientated practices around competitive or protective funding behaviour; low levels of staff competence; heavy caseloads; and responding to their own service or agency procedures and protocols rather than supporting the young person and their family. Individual government departments involved in the process also find it difficult to collaborate particularly with funding because of a "silo mentality."

In the British context, the final summary of an important research study – *Bridging the Divide at Transition* (2003), part of a project collaboration between the Home Farm Trust and the Norah Fry Research Centre – provided a damning review of the effectiveness of the transition planning process, as seen through the eyes of parents. The findings are summarised below:

- A fifth of youngsters had left school without a transition plan.
- Almost half the young people had little or no involvement in planning for their future.
- Lack of planning led to uncertainty and stress for some families.
- The quality of transition planning varied widely; in some cases it was ad hoc, confused and uncoordinated.

- The topics covered in transition planning were often quite different from those families considered to be important.
- For many young people, key issues (for example, transfer to adult health or social services) had still not been addressed by the time they left school.
- Whether or not young people had received transition planning made little difference to what happened to them after leaving school.
- There were few post-school options available to young people, particularly in relation to housing and employment.
- There was a lack of easily accessible information for parents and young people about what future possibilities might be.
- Concerns raised by the young people and their families which inhibited their transition were personal safety and risk, money matters (including benefits) and transport.

Importantly, the above parents' perspectives from the United Kingdom echo findings five years later from the Wayne Francis Charitable Trust Transition Project for Disabled Students in Christchurch, New Zealand (Cleland et al., 2008). This study found there was a lack of coordination by services; planning was generally too late and not student centred; parents and students felt that getting the right information at the right time was problematic; there was a lack of work experiences or tertiary courses undertaken during school; and there were very few options post school apart from attendance at vocational service day centres.

Many researchers have expressed concerns about the lack of involvement of young people with learning disability in the transition planning process, arguing that they should be actively engaged in determining their own future goals (Dee, 2006; Thoma, Rogan and Baker, 2001; Winn & Hay, 2009). Research indicates that further education and training after leaving school can increase opportunities for students with disability to secure eventual employment. However, it is evident that there are major barriers for young people with learning disability seeking to move into further and higher education (Hay & Winn, 2005; McLaren & Kearney, 2009; O'Connor et al., 2012). Barriers include lack of knowledge about further education

options and funding sources; social isolation from peers; and attitudes and exclusionary criteria of colleges and universities (Madaus, 2006). Many researchers find that young people with disability are not adequately consulted about their goals and aspirations. Parents and professionals often control decisions about their futures (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003; Smart, 2004). There is often a tension between whether the academic or the functional curriculum is more relevant and useful in determining post-school outcomes (Browder, Spooner, Wakeman, Trela, & Baker, 2006; Ayres, Lowrey, Douglas, & Sievers, 2011). Moon, Grigal and Neubert (2001) reinforce the need for students with learning disability to be educated in adult settings past the school-leaving age of their peers without disability.

In a New Zealand context, students and parents in the *Young Persons Deciding Their Own Futures Project* (Cleland, Rickerby, & Morton, 2004) in Christchurch identified the following systemic barriers within some schools:

- Insufficient funding, resources and services are available to coordinate transition and support students in schools.
- Some students' learning requirements are not taken seriously and do not access relevant curriculum.
- Students and parents are often unable to make an informed decision about transition.
- Staff, students and families lack information on disability supports for tertiary study and employment.
- Some staff lack understanding of current disability issues, philosophies, student needs and support.
- During work experience, some students wondered what skills they were learning and felt exploited.

As has been described in this section, overcoming barriers to effective transition planning requires a coordinated response that puts the student and family at the centre of the process and actively supports them well before they leave school to well after they have left. Putting the student at the centre of the transition process is now discussed, along with the importance

of the parents (or caregivers) and family role in a person-centred approach to transition planning (Kim & Turnbull, 2004).

Student-centred transition

The argument for putting the young person at the centre of the transition planning process is well established in the literature. However, there are many different interpretations and tensions regarding exactly what being at the centre means. O'Brien and Lovett (1992, p. 5) describe person-centred planning as "a family of approaches to organising and guiding community change in alliance with people with disability and their families and friends." These new approaches emerged in the early 1980s as a way for services, mostly for adults with disability, to plan and deliver appropriately. Being "student centred" or using a "student-centred approach" means ensuring that everything is based upon what is important to the young person, from their own perspective. It provides a structure to help support providers continually listen and learn about what is important to the young person, now and in the future, and act on this in alliance with friends and family and significant others. It requires a fundamental shift of thinking from a "power over" relationship to a "power with" relationship. This shift in thinking has historically been a challenge for schools and services that have traditionally supported people with learning disability.

Over the last 30 years, student-centred approaches have been interpreted in many ways in the literature. "Student-centred" is a term used by educational, vocational and residential services looking to design responsive service delivery systems for people with learning disability (O'Brien, O'Brien, & Mount, 1997; Mansell & Beadle-Brown, 2005). In the United Kingdom and many states in the United States, person-centred approaches within services have become mandatory. A large-scale evaluation of the outcomes of person-centred planning for people with learning disability was conducted in the United Kingdom (Robertson, Emerson, Hatton, Elliott, McIntosh, Swift et al., 2005). The study examined the costs of introducing such a system and found that although many people with learning disability didn't have a plan, those who did benefited considerably in terms of increased social networks, community-based activities and choice. It found that well-trained professionals who facilitated effectively with the right values had a marked influence on improved outcomes (Robertson et al., 2005).

Some issues in student-centred planning

Student-centred planning, then, is a key element in the transition for students with learning disability. To implement it effectively in education requires strong relationships, effective “whole-school” systems and an investment in educational equity. For the students with learning disability considered in this study, the key planning process utilised in schools has been the IEP. It is my view that in New Zealand schools, there is confusion surrounding the IEP process and how, where and when it embraces or morphs into the Individual Transition Planning (ITP) process – or, indeed, whether it does or should. The result is that teachers and other professionals working in the field often lack the understanding, skills and knowledge to effectively utilise an authentic, student-centred approach. Rather than encouraging collaboration, school professionals may actually engage in actions that are disempowering to students and parents by overtly asserting their expert power (Turnbull & Turnbull, 2001). This leads to a “we-they posture” in planning and goal setting (Turnbull & Turnbull, 2004, p. 82), which makes shared collaboration difficult. In a recent study in the United States of the perceptions of 1,638 participants from 393 secondary school IEP meetings, Martin, Marshall, and Sale (2004) reported that although students seemed to attend their IEP meetings more frequently as a result of IDEA’s legislative transition mandates, their meaningful participation was still lacking.

In New Zealand, the IEP has historically been the planning tool for students with special educational needs. However, as yet there is no mandatory requirement for transition planning within the IEP process, such as there is in the United States and the United Kingdom. I believe that this leaves secondary and special schools confused about when IEP planning should focus on transition or if they are to be seen as separate processes. Although there is no reliable data available nationally, my experience working and supporting schools as manager of the LSTS in Christchurch leads me to conclude that students do not always attend their transition planning meetings – and where they are present; they may be the focus of professional attention but have little meaningful control.

Incorporating student-centred planning in the ITP process

For over 20 years, international best practice has aligned with students attending their own IEP or ITP meetings in schools. What form of active participation the student has in these meetings is critical to the overall success of the planning process, but this requires professionals to have both the vision and the specific expertise (Grigal, Test, Beattie, & Wood, 1997). Martin and Marshall (1996) describe 11 steps to transition planning led by the student. Bates et al. (2001) suggest an adapted 10 steps, placing the post-school vision of the student as the starting point.

The importance of prior preparation and planning cannot be underestimated, as it holds the key to successful implementation of the ITP. The ITP is a living document that provides a clear pathway to achieve the student's post-school goals. Importantly, it is a collaborative tool that the whole "team" contributes to. This team might consist of any of the following: student, parents or caregivers; other family; professionals; paraprofessionals; friends or peers; and significant others. According to Holburn (2002), student-centred planning has the ability to bring together the important people in a student's life and create a vision for the ITP. What makes student-centred planning successful is the almost complete absence of "the professional authority hierarchy and deficit orientation characteristic of a clinical team planning process" (Holburn, 2002, p. 251).

Best practice in student-centred planning

Kim and Turnbull (2004) identified the main approaches to person-centred planning, drawing from a wide range of research in their 2004 article on transition. Approaches they referred to included Individual Service design (O'Brien & Lovett, 1992); Person Futures Planning (O'Brien & Lovett, 1992); Life-Style Planning (O'Brien & Lovett, 1992); Essential Lifestyle Planning (Smull & Harrison, 1992); Planning Alternative Lifestyles with Hope (Pearpoint, O'Brien, & Forest, 1993); and Group Action Planning (Blue-Banning, Turnbull, & Pereira, 2000). Drawing from the work of these people, and also Schwartz, Holburn and Jacobson (2000), I suggest five key features of student-centred planning:

1. The student is at the centre of and is empowered through the process. Student-centred planning is concerned with rights, responsibilities and opportunities, so it

requires careful listening and knowledge about how best to support the individual to the next stage in their life. The student is empowered to make real choices and decisions concerning their future life.

2. Family members and friends are full partners. Student-centred planning puts people in the context of their family and communities and recognises the explicit value their contribution brings. It also acknowledges the possible tensions between the parent's aspirations and those of their child.
3. Student-centred planning reflects a person's capabilities, what is important to a person – now and for the future – and what support is required to make a valued, purposeful contribution to the community.
4. Student-centred planning is an ongoing collaborative process of working together by all stakeholders to make changes that the student and those close to them agree will support their journey towards a good life.
5. Student-centred planning leads to continual listening, learning and action and helps the person to get what they want out of life. It also informs how schools and associated stakeholders and services respond to a holistic view of the young person.

So far in this chapter, I have discussed the transition process for students with learning disability, highlighting its importance within education – specifically career and transition education – as well as the difficulties associated with it. The importance of transition planning was highlighted, along with some of the barriers that young people and their families might face. I showed that schools often have divergent systems for supporting students with learning disability, and that decisions about future pathways post school are frequently mediated by systemic issues related to low expectations; poor planning; a lack of professional development among teachers; and school career specialists abdicating their responsibility for supporting this group of students in accessing special education professionals and external services. I provided a brief overview of the importance of student-centred planning in the transition process and discussed what is considered best practice. I now move on to explore the influence of the construct of self-determination on transition, because of its close link with student-centred planning.

Self-determination and transition

Self-determination as a construct has been conspicuous in the literature on transition. Wehmeyer (1996, p. 22) defined self-determination as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from negative external influences.” He went on to say that these meaningful decisions and choices are generally made in relation to quality of life in the home, school, work and community. Self-determination refers to the ability of students to advocate, evaluate, and make choices in their lives (Grigal, Neubert, Moon, & Graham, 2003). The close relationship between post-school outcomes and self-determination is clearly promoted in the literature (Algozzine Browder, Karvonen, Test & Wood, 2001; Wehmeyer & Palmer, 2003). Bach (2000) provided a less formal description, in which people are supported to form meaningful relationships and to follow their goals and dreams. Turnbull and Turnbull (2001) defined self-determination as a process where people “experience quality of life consistent with their own preferences, strengths and needs” (p. 56). Research by Aichroth et al. (2002), Zhang (2005) and Chambers et al. (2007) found that greater self-determination led to improved education and employment opportunities and a sense of community belonging.

However, the concept of self-determination has been criticised for emphasising individual choice and control at the expense of the community (Dee, 2006). Browder, Wood, Test, Karvonen and Algozzine (2001) argued for a concept of self-determination that promotes the importance of cultural and family ties. Armstrong (2003) argued for self-determining action that reflects a belief in and commitment to citizenship. Malian and Nevin (2002) put forward the view that a more dynamic and time-related understanding of the development of self-determination is required.

Self-determination, then, is a much debated construct within the learning disability landscape (Laragy, 2004; Turnbull & Turnbull, 2006; Smith & Routel, 2010). It is often reviewed in the literature in order to understand what control and choice students with learning disability have as they make the turbulent transition to post-school life. The literature surrounding the construct of self-determination varies according to who is asked, whether that be parents, researchers, educators or the myriad of transition related professionals (Wehmeyer et al., 2003; Shogren et al., 2005). This has led to different definitions and, consequently, confusion

about how to best create the environment, opportunities, tools and methods for students to self-determine (Karvonen, et al., 2004). In the field of education, self-determination is seen as something that can be taught, a set of skills and knowledge (Zhang, Wehmeyer, & Chen, 2005). However, there are differing views beyond the perspectives of educators and related human service professionals. The influence of cultural differences has been pointed out (Zhang, 2006), as has debate over terminology (Sunderland, 2007) and context (Wilder, Jackson & Smith, 2001).

Information regarding options and opportunities is critical for students with learning disability in being able to self-determine. If they do not know what options are available and have the opportunity to go about achieving them, they will not be able to self-determine (Trainor, 2005). This may be described as “you don’t know what you don’t know.” This is the same for anybody who wants to make informed decisions about their future lives. Importantly, if the opportunities are not there to begin with, then making decisions about future options becomes an arbitrary exercise. Another important aspect when providing information to students and parents is the need to provide the right information at the right time through effective planning processes, thereby further supporting self-determination in the transition process.

Transition planning, then, is a key vehicle in schools for promoting opportunities for self-determination (Halpern, 1999). Shaddock (2000) described the move from “planning for” to “planning with” and “planning by” people with disability. When transition planning goals reflect professional perspectives rather than what is preferred by students and families, it is likely the goals or outcomes will not be achieved (Wehman, Moon, Everson, Wood, & Barcus, 1988). Student-centred planning occurs when professional decision-making is restricted and the student’s goals and aspirations are promoted (Mount & O’Brien, 2002; Ritchie, 2002; Sanderson, 2002; Wehmeyer, 2002). Empowering students to self-determine through the planning process is therefore crucial in providing the best opportunities for them to achieve their post-school goals. Nonetheless, the specific knowledge, skills and attitudes of teachers and associated professionals and paraprofessionals have a critical role to play in ensuring that the opportunity for self-determination is presented. Promoting self-determination through the transition process requires that students with learning disability play a central role in the transition planning process and that their “voice” is heard (Kohler &

Field, 2003). It does not, however, mean that students will make decisions independently, but rather within a collaborative team approach with parents, family, friends, associated professionals and other significant people as appropriate (Field & Hoffman, 2007). The team focus in providing positive, nurturing relationships is a key factor that contributes to self-determination. Shared goal planning works best when it is a process rather than an “event” and involves ongoing conversations with the student. The quality of informed relationships that support the student is critical in promoting self-determination. Schools reflecting on inclusive practices such as student planning and authentic voice in the IEP process can also support self-determination. Ryan and Deci (2000) found that contexts that support interdependency build greater internal motivation and self-determination.

As a fundamental component on which most transition services are based, self-determination is seen as socially and culturally mediated within a landscape controlled by the social and economic power-brokers of neoliberalism.

Does self-determination refer to a curriculum that teaches students with disabilities to be self-directed problem solvers, a technique for redirecting funding streams so that adults with disabilities can control the dollars allocated for their supports and services, or a philosophy grounded in democratic values and constitutional principles of autonomy and liberty? Or is it two or even all three of these? (Turnbull & Turnbull, 2006, p. 6)

Neoliberalism and other forms of social and economic management expect students with learning disability to define themselves as independent, self-determined and empowered people. I argue students with learning disability find themselves caught in a social space where professional interventions demand individual action without real opportunity to do so because of an exclusionary education landscape. This has resulted in the effect of self-determination being inextricably linked with the neoliberal project (Douse, 2009).

The view that the definition of self-determination as choice, control and power over one's life can be taught purely as a set of skills is naive. Instead, as Smith & Routel (2010) posit, it is more about who controls that definition. Self-determination is individually and culturally relative. Therefore, vehicles like person-centred planning processes, circles of support, individualised funding, facilitation and brokerage support are essential elements in bringing choice, control and power into the lives of young people with intellectual disability and their

families (Smith, 2003; Smith & Routel, 2010). Through this form of endeavour, young people with intellectual disability, their families and allies can begin to take control of that definition. However, these processes are only just beginning to be included in policy guidance and are a long way off from being realised in practice for students with learning disability in New Zealand schools.

Policy and legislative influences on transition in New Zealand

Despite government policy and legislative rhetoric, the gap between policy and practice is evident not only in New Zealand but most OECD countries. In relation to students with learning disability, Mittler (2007) has provided a United Kingdom perspective:

We now have some hard data on how families and young people themselves experience the process of transition which illustrate the yawning gap between policy and practice which has been experienced by young people with learning disabilities over many decades. (p. 17)

In New Zealand, the New Zealand Disability Strategy has influenced how the Ministry of Education (through its Special Education division) defined the outcomes it was seeking to achieve for special education in New Zealand. Bennie (2005, p. 100), who is a MoE special education district manager, described how “intermediate outcomes have been defined as presence, participation and quality learning which are seen as leading to achievement, community participation and, significantly, workforce participation for young people with special needs.” Yet, as earlier described in this thesis, New Zealand secondary-aged students with learning disability continue to be overwhelmingly educated in a segregated setting, whether that is in a special school or in a unit or learning support class on a secondary school site.

The Ministry of Education has described its goals for education as “building a world-leading education system that equips all New Zealanders with the knowledge, skills, and values to be successful citizens in the 21st-century” (Ministry of Education, 2012). However, this policy rhetoric has largely failed to influence students with learning disability transitioning from school. Further to this, all schools are required by the National Administration Guidelines (NAGs) (Ministry of Education, 2003, p. 7) to

provide appropriate career education and guidance for all students in Year 7 and above, with a particular emphasis on specific career guidance for those students who have been identified by the school as being at risk of leaving school unprepared for the transition to the workplace or further education/training.

This guideline makes me question whether students with learning disability are considered to require a career and transition to further education, training and employment. In the findings chapters of this thesis, I make the argument that too often students with learning disability are not seen as requiring a career because of negative assumptions and low expectations concerning their capabilities. It is not expected that they will go on to further education, training and employment; rather, they will transition into a vocational service day centre.

All these themes can be defined as the dynamic between the range of provision available and the young person's needs and aspirations. O'Bryan, Simons, Beyer and Grove (2000) described effective outcomes where the needs and aspirations of the young people are assessed and provision developed accordingly. My professional experience in New Zealand has been too often the opposite, where the young person's future path is dictated by the provision available under the control of education, social and welfare systems (Kendrick, 2009).

Transition to what?

We make many transitions through our lives, but it is generally accepted that one of the most difficult for any young person is that from school to post-school life. For students with disability, this transition presents additional challenges in achieving a purposeful life as valued people in the community (Ferguson & Ferguson, 2000; Hornby & Kidd, 2001; Byers et al., 2002; Heslop et al., 2002; Cleland et al., 2004; Kim & Turnbull, 2004; Tisdall, 2004; Dee, 2006; Kaehne & Beyer, 2008; Cleland et al., 2009; Gladstone & Thomas, 2009; Meadows, 2009; Winn & Hay, 2009; Cleland & Smith, 2010). For students with learning disability in New Zealand, this transition is even more challenging and requires overcoming many barriers (Bray, 2003; Mirfin-Veitch, 2003; Bennie, 2005). This section will describe the landscape in New Zealand for students with learning disability transitioning from school within the context of competing tensions between social welfare agendas and the young people's desire for economic and social participation.

New Zealand-specific research on transition to post-school life for students with learning disability

There have been a small but significant number of New Zealand studies in the last 20 years that highlight the need for more effective transitions to adulthood for students with learning disability (Bennie, 1996, 1997, 2005; Bray, 2003; Mirfin-Veitch, 2003; Cleland et al., 2008). In 2003, Bray conducted a review of the literature prepared for the New Zealand National Advisory Committee on Health and Disability to inform its project on services for adults with learning disability. Her conclusions were premised on the assertion that work is the route for economic and social integration. However, her findings found “that most adults with learning disability are deemed unable to work and spend their days in segregated services, some of which provide some ‘sheltered work’ for no or minimal work” (p. 99). She goes on to say that the model of supported employment

can enable adults with an intellectual disability to work in paid jobs in ordinary settings, with positive economic, social and personal outcomes. The evidence that is available also supports the cost-benefits and cost-effectiveness of supported employment services over time. At the same time, the evidence from countries which have sought to change their vocational service system shows that it is a difficult and complex endeavour. (p. 99)

In the early 1990s in New Zealand, the supported employment model described above was promoted as the vehicle for providing people with learning disability with sustainable paid employment. In a paper published for the 25th Asia-Pacific International Seminar on Special Education, Bennie (2005) outlined the poor employment opportunities for people with learning disability generally and highlighted – along with Bray (2003) and Mirfin-Veitch (2003) – that supported employment is the model most likely to provide positive employment outcomes for young people with learning disability. Nearly 20 years on from Bennie’s (1996) thesis on supported employment in New Zealand, it is difficult to find any reliable data on improved outcomes for people with learning disability in regard to employment. Bennie (2005) estimated that less than 20% of people with learning disability are in the paid workforce, and most of those would be in part-time, low wage employment (p. 100). In addition, those people with learning disability would tend to have a mild or moderate learning disability and therefore not represent the group described in this thesis. Anecdotally, my

experience suggests that very few people with a high needs learning disability are in paid employment of any form.

A holistic view of the transition process

It is important to acknowledge that paid employment, while an important aspect, is only one potentially measureable outcome of the transition to adult life, and that a holistic view of a person's life is crucial. A large number of international studies have considered parts of a person's life apart from employment, such as levels of independence; self-determination; social networks; health and well-being; and living arrangements. People with learning disability living in community settings participate more than people living in a segregated setting, but their participation level is still much lower than people without disability and other disability groups (Verdonschot, de Witte, Reichrath & Buntinx et al., 2009). Halpern (1989) suggests a strong community aspect when seeking outcomes of the transition planning process and describes social networks, developing relationships and living in the community. Halpern's research found that the young people themselves considered social networks to be the most important aspect of how people perceive their life satisfaction. Mirfin-Veitch (2003) conducted a review for the New Zealand National Advisory Committee on Health and Disability that explored *Education for Adults with an Intellectual Disability (Including Transition to Adulthood)*. Her review acknowledged the lack of New Zealand-specific research, but drew on the international literature to highlight transition as a process and show the importance of transition planning and taking a holistic view of a young person's life. She concluded:

Transition planning needs to incorporate a range of options and activities that include a focus on employment, but that also consider other aspects of adult life including adult education, social relationships, supported living, and community participation and leisure. (p. 30)

Current landscape for transition in Christchurch, New Zealand for students with learning disability

Further research in the area of transition was carried out in Christchurch, New Zealand, by the Wayne Francis Charitable Trust, who commissioned Creative Solutions to undertake a

transition project in 2007–2008. This was as a result of youth services in Christchurch identifying systemic barriers to the transition of young people with disability. The Wayne Francis Charitable Trust was seeking to enhance the effective transition of students with disability into employment, further education and training, and community settings. A literature review was conducted and a programme of consultation facilitated by myself and the project manager, Grant Cleland of Creative Solutions. Building on the previous work of Bray, Mirfin-Veitch and Bennie, as well as international research, the findings from the Christchurch study were collated in a report and a 10-point best practice framework for students with disability, which is reproduced below:

Best Practice Framework for Transition of Disabled Students (Cleland, Gladstone & Todd, 2008)

- Transition starts to occur no later than the age of 14 years and is part of a specific transition planning process that aims to develop academic potential as well as functional transition skills.
- The process is driven by the student/whanau and the student is actively engaged in determining/implementing their future goals.
- Partnerships between the school and community supports are developed at least 2 years before the young person leaves school.
- The transition programme is integrated within the structure of general education rather than as a separate and parallel programme.
- The process identifies and overcomes barriers to the disabled students learning and support.
- The students/whanau are offered information and support that opens the door to a wider range of inclusive community based options.

- A clear distinction is made between the transition needs of the young person and those of their family.
- Functional transition skills are in the curriculum and practised at home.
- Those at school after 18 years old receive services in adult settings.
- The outcomes of the transition planning process are regularly evaluated

The Wayne Francis Charitable Trust work resulted in two local forums taking place in late 2008, where representatives from government and community agencies and services involved in the transition of students with disability, including young people and parents, came together to find a way forward from the recommendations highlighted in the report. As a result of these forums, it was decided that a working party would be formed who would make recommendations on how best to move forward. The recommendations from this working party saw the local Ministry of Education office coordinate the setting up of a new transition service for a group of Christchurch schools, which was based on a lead school model and co-funded by the local MoE office and the participating schools, who contributed a small portion of their ORS full-time teacher entitlement (0.1 FTE). The service had governance from a multi-agency steering group comprised of key stakeholders, including young people; parents; principals; government agencies; Chambers of Commerce, tertiary, and community representatives; and others. The Lead School Transition Service (LSTS) was established in July 2009 with the expressed aim of building capacity and the capability of schools to better support students with disability in the transition to post-school life. It began with a consortium of eight special and secondary schools. The 10-point best practice framework quoted above underpinned the service's work. It is important to appreciate that the service was for all students with special educational needs, both ORS-funded and not. This recognised that there were a significant number of students who fell through the net during the transition from school and the requirement to also support them was important.

The LSTS has achieved recognition in Christchurch and nationally in supporting schools to adopt a more holistic, focused, planned and personalised approach to the transition of students with disability. The transition officials inter-agency group in Wellington is a cross-government group who meet regularly to consider how best to promote a coordinated

approach to the transition to adulthood. This group had taken on the LSTS as their “learning in action” project in drawing practical solutions from the service’s work with schools and government agencies and services. The recent Ministry of Education response to the review of special education *Success for All – Every School, Every Child* (2010b) refers to the LSTS as a model of best practice.

The Ministry of Education (2010a) *Statement of Intent 2010–2015* makes reference to working with the inter-agency group on transition, stating that they “continue to work with the interagency transition group to improve current policy and practice around transition from school to post-school life for young people with disabilities” (p. 19). The statement identifies the success criteria for this as “more students transitioning to further education, training or work” and “fewer young people with disabilities remaining in school until the age of 21” (p. 19). It goes on to say:

Some schools manage transitions extremely well. For example, the schools involved in the Christchurch Lead School Transition Service Pilot are working together to develop an across-school transition service using a best practice framework, but more needs to be done so that all schools are skilled at managing transitions. (p. 19)

The fact that I managed the LSTS for three years while doing my PhD part-time gave me an insight into the workings of education policy and how it may translate in practice. My firm belief is that the service achieved considerable traction in local schools and the wider community through building effective relationships. Its overriding focus was to position the student and their family at the centre of the process and build a holistic, relational and inclusive framework around them. A framework was developed to build sustainable, equitable relationships among all the stakeholders involved to best support the vision of the young person and their family. The fact that this service no longer exists (as of June 2013) illustrates the power and control exerted by special education officials within the MoE. I return to this matter in the final chapter of this thesis.

There is a great deal of literature regarding what is effective practice in student-centred transition planning. However, the vast majority of it provides a professional’s perspective. That professional perspective usually originates from a special education perspective. As such, it highlights the disjuncture between mainstream transition and special education

transition processes. I have suggested that this is because the word “career” is rarely used when working with students with learning disability on planning for post-school life.

Part 1 of this chapter began with a definition of the term transition, emphasising that this thesis is interested in the transition process from school to post-school life. Importantly, I premised an effective transition process on a holistic view of a person’s life and argued that while further, education, training and employment are important, good transition planning must consider other aspects like social networks and friends; living and housing; leisure; health and well-being; and finding a sense of belonging and purpose in life.

I highlighted the tensions for students with learning disability when the journey to post-school life is not seen within a “whole-school” approach to careers and transition planning. I also alluded to the fact that if students with learning disability are not required to have a career, then their transition planning and pathway most often leads directly into a vocational service day centre. I made the point that effective student-centred career and transition planning is not embedded in New Zealand schools, whether these are special or secondary schools. For young people with learning disability, there is a need for targeted, student-centred support if they are to transition successfully to the next stage in their lives. To achieve this, we need to know what kind of lives these young people want and how we can best support their journeys (Meininger & Reinders, 2004). I made the point that education and its institutions are well placed to influence what educationalists, policymakers and researchers clearly define and promote as a crucial phase in a student’s life.

I also suggested that students with learning disability are largely educated in a form of “parallel place,” whether they are enrolled in a special or a secondary school. This is evident in the focus on age-related rather than vertical service policy and provision. If we agree that good transitions are premised on a holistic view of a person’s life, then it makes sense to acknowledge that what is required is the development of more holistic services that promote strong relationships at the micro and macro level. The development of effective policy interventions should be based on a much clearer understanding of how these young people actually think and behave, and the kind of life they desire.

A BRIEF HISTORY OF CONTEMPORARY SOCIAL RESPONSES TO PEOPLE WITH LEARNING DISABILITY

I now explore contemporary social responses to people with learning disability. I consider the recent history, over the last 30 years or so, of how people with learning disability have been managed. The special education and social welfare service-orientated approach in managing the lives of the young people in this study profoundly influences their journey towards a good life. I consider this important in providing a history and background to the continuing influences that permeate education and social welfare responses to students and young people with learning disability.

The development of the “psy-complex”

The development of psy-complex has been linked to Ingleby (1984). It describes a group of services for the management of what was described as “mental deficiency.” The term generally encompasses education, psychology and social work services, the discourses of which span family, school and workplace contexts. The psy-complex was further developed by Rose (1985, 1986) to refer to “all those disciplines concerned with the troubles and disorders of conduct, emotion and thought and the conditions for mental health” (1986, p. 284). Since the 1960s, interventions by professionals within the psy-complex have influenced new definitions of the “problem” of mental disorder. Research shifted its focus the organic to the social functioning of the individual. In service provision, this prompted a shift from treatment to training – what became known as behaviourist models and practices. The emphasis was on how people with learning disability could be made “normal.” Underlying this was the assumption that people could be educated or trained to lead a more “normal” life (Ryan & Thomas, 1987, p. 122). In education, behaviourist forms of teaching began around this time, influencing early special education and reflecting changing understandings within disability studies. Behaviour modification techniques legitimised new roles for professional and support staff, from care to training. Control and modification of the deviant individual became the practitioner’s goal, an approach which Matthews and Matthews (2005) considered to be punishment-focused. Behaviour modification as a training approach for people with learning disability during the 1960 and 1970s was evidence of the growing power

of the psy-complex. These techniques greatly influenced special education theory and practice during these years.

In the last 30 years, services developed by the psy-complex have increasingly focused on the importance of the development of social and behavioural competence (Rapley & Ridgeway, 1998, p. 455). Complex systems have also been devised and endorsed by government to evaluate service efficiency (Rapley & Ridgeway 1998, p. 455). The professional “expert” paradigm has become deeply embedded in policy and practice over time and, importantly, has been identified by many people with learning disability as a critical point of resistance (Douse, 2009). The emergence of these professions raised questions about whether the institution was the best place for those deemed “socially flawed.” In the 1970s, policymakers and parent groups began to demand new forms of residential and educational placement outside the institution for people with learning disability. Through this deinstitutionalisation process, a new paradigm emerged: “normalisation,” the language of which became utilised by the growing corporate and managerial approach to social policy for people with learning disability.

Normalisation

Normalisation and SRV continue to influence service provision for people with learning disability in New Zealand and other Western countries. How far it has influenced Western government’s social policy since the 1980s is less clear, with some writers questioning the degree of influence (Douse, 2009; Meekosha, 1998). The origins of normalisation can be attributed to Bank-Mikkelsen, writing in the late 1960s in Denmark, and Nirje (1976), who began to discuss normal patterns of living where people live, work and enjoy leisure in different places in “ordinary life.” Brown and Smith (1992, p. 3) saw this as “ensuring equality on a number of traditional social indicators of quality of life including housing, education, work and leisure.” Johnson and Walmsley with Wolfe (2010) described a changing landscape; as social norms have changed, so too have the parameters of normalisation. They used the example of Nirje, who in 1980 “specified the right to the development of heterosexual relationships, including the right to marry. In the early 21st century this would by definition extend to same sex relationships, including the right to civil partnership” (Johnson & Walmsley with Wolfe, 2010, p. 68).

Wolfensberger saw the potential of the concept of normalisation as a principle that would counteract the devalued ways in which society, including human service providers, tended to think about people with learning disability. While Wolfenberger's analysis of mental retardation as "deviancy" was not unique, his emphasis on the role of ideology in human service planning and its relation to the normalisation principle was timely. Wolfensberger, already known as a champion of new thinking about mental retardation (Trent, 1995), developed, in 1972, *The Principle of Normalisation in Human Services* (Wolfensberger, 1972). Wolfensberger's work was largely a result of his own psychological training and the American sociological traditions of the 1950s and 1960s, including the functionalist analysis of Parsons (1951), the symbolic interactionism of Mead (1934) and the work of Goffman (1963) on deviance, labelling and stigma. Wolfensberger (1972, p. 13) saw people with learning disability as deviant, not because of their own choosing, but because their observed quality was seen as negatively value-charged. Virtually all aspects of people with learning disability's lives – from residence in institutions and education in segregated schools to employment in sheltered workshops – signalled uniquely devalued qualities.

According to Caruso and Osburn (2011), the origins of normalisation can still be seen in many so-called "best practices," such as person-centred planning; circles of support and mentoring and individual education plans. Caruso and Osburn provide a critique of how normalisation and SRV have been much used and abused by the implementers of "best practices," who take individual parts and fail to consider the whole. They contend that this is mostly because funding-capped bureaucratic systems don't have the resources or desire to implement these approaches fully as intended.

SRV

In the early 1980s, Wolfensberger (1983) introduced the broader concept of SRV to combat what he saw as growing misinterpretation of normalisation. This new concept made use of role theory more explicitly than did normalisation theory. It also stressed the relationships between personal competencies, social expectations and social perceptions. The essential problem with SRV for many – even those who were persuaded by the fundamental arguments of SRV – was its complexity (Lemay, 2005). I would argue that transforming complex ideas into practice is not often done well by human services personnel and policymakers. SRV

could be described as a theoretical framework based on empirical knowledge, drawing on multiple theories in sociology, education and psychology. The central theoretical base for understanding SRV was the notion that a person could be cast in positive or negative roles. Wolfensberger (1992) described social roles as “a socially expected pattern of behaviours, responsibilities, expectations and privileges” (p. 13).

Wolfensberger developed a system for service providers to support people with learning disability to assume positive or socially valued roles that would integrate them into culturally normative settings (Trent, 1995, p. 263). He set standards on issues such as rights, individuality, social integration and typical patterns of living (Felce et al., 1998, p. 11). In support of this effort, a comprehensive, intricate and prescriptive training programme for service professionals was developed, first called Programme Analysis of Service Systems (PASS) and later Programme Analysis of Service Systems Implementation of Normalisation Goals (PASSING). It was then used to assess how well services had met the exacting standards of SRV.

Wolfensberger’s work was founded on good intent, and both normalisation’s and SRV’s overarching goal was dignity and respect for people with learning disability. Wolfensberger believed that integrating people with learning disability into the community was the way to social acceptance, yet some people saw his actions as vitriolic (Trent, 1995). Significantly, there has been much debate concerning the efficacy of SRV when policymakers and services do not fully consider or understand the impact such technologies have on the lives of people with learning disability (Johnson & Walmsley with Wolfe, 2010, p. 69). Johnson and Walmsley with Wolfe (2010, p. 70) saw this as “the failure to consider whether people with learning disability as individuals wanted prescribed normalisation, or to think about the multifarious communities to which people belong.” Normalisation and SRV owe much to Goffman’s *Stigma* (1990), which presents stigma as a challenge for the stigmatised person to act to reduce the potential for embarrassment. From this perspective, the responsibility must be on the stigmatised person to act (Goffman, 1990). Thus, the social perception of the stigma leads to social devaluation, which then creates a cycle that is extremely difficult to break. For people with learning disability, the work of Edgerton –specifically his 1967 study, *The Cloak of Competence* – was one of the first times a researcher had interviewed institutionalised people and let them to speak for themselves. However, he saw their lives from his own binary

perspective or lens: you are either a person with learning disability, or you are “normal.” From his perspective, then, the life goal of the person with learning disability must be to gain entry into the “normal world,” with the array of policy, legislation and practice aimed at promoting this “passing” into that world and staying there (Johnson & Walmsley with Wolfe, 2010, p. 71). Oliver (1996) pointed out that Goffman’s use of stigma is based on perceptions of the oppressor rather than the oppressed, maintaining that stigma is an issue of exploitation and oppression rather than avoidance as Goffman suggested. Finkelstein (1980) argued that Goffman’s work fails to move beyond the individual. It takes as given the segregation and inferior status of stigmatised groups and individuals ingrained in capitalist social relations without seriously addressing questions of why this might be.

Chappell (1992) provided a powerful critique of normalisation and SRV, arguing that it does not provide a theory of disability that takes into account the material constraints in the lives of people with learning disability. She also argued that SRV is dominated by empiricism and the priorities of professionals; further, it is functionalist and idealistic both in its adoption of interactionist concerns with deviance, labelling and stigma and its emphasis on attitudes and values (Chappell 1992, p. 39). In addition, ordinary life in the community as determined within the rationality of SRV continues to rely on power relations where life-plans are mapped out by professionals (Chappell 1997, p. 48). Normalisation can only provide people with disability with the opportunity for valued social roles in an unequal society. In contrast, materialist social theory offers people with disability the opportunity to transform their own lives and so transform society, so that all roles are valued (Oliver, 1996, p. 28). Clegg (1998) argued that SRV assumes that all humans are the same and have the same set of values and therefore by definition this must act against difference. SRV has often been promoted as a liberating paradigm, offering new hope and valued lives for people with learning disability and others deemed “not normal.” However, it has been claimed that it extends bio-medical disciplinary practices by its emphasis on the reduction of devaluation through the prevention of difference (Meekosha, 1998). In addition to the regulation of the abnormal bodies of people with disability, SRV is a technique that assumes a particular form of human self who is “rampantly autonomous, competent and rational” (Campbell, 1998, p. 1). Critiques of SRV have generally focused on its methodological flaws, either as a deviancy theory (Graycar &

Dorsch, 1986; Brown & Smith, 1992; Bleasdale, 1996; Campbell, 1998) or in its construction of disability (Branson & Miller, 1989; Oliver, 1996; Rapley & Baldwin, 1995).

The rhetoric of SRV has failed to prevent policy, service design and development from acting in any way other than to reinforce a framework for life that requires people with learning disability to conform while denying their difference. However, SRV can be acknowledged at least in part as a driver for the change in the social and locational organisation of service provision for people with learning disability through deinstitutionalisation. This occurred alongside the growing influence of the parent voice and the reality that with governments restricting funding and a fiscal crisis looming, alternatives needed to be found. Institutions became discredited, not only because of the economic, social and moral failures of the solution of grouping large numbers of people with learning disability, but because the world was embracing rampant individualism (Johnson & Walmsley with Wolfe, 2010).

Deinstitutionalisation

In the early to middle years of the 20th century, large institutions for people with learning disability were focused on segregation, control and eugenics. Moves to separate the “mentally ill” from the “mentally deficient” saw the emergence of institutions exclusively for people with learning disability. In the New Zealand context, the Mental Defectives Amendment Bill of 1928 allowed certain institutions to be set aside for the care and training of “mentally deficient” children. Templeton Farm School, which was located outside of Christchurch, opened in 1929 and became the first such institution to be established under the legislation. Even with the existence of specialist hospitals in New Zealand, nearly half of the institutional population of people with an learning disability in 1981 lived in “intellectual handicap” wards within psychiatric hospitals (Mirfin-Veitch, 2005). Thomson (1995) described the purposes of institutions as being “to meet the basic demands of life, shelter people with an intellectual disability from the demands of society and relieve society, particularly families, from the burden of dealing with people with an intellectual disability” (p. 85).

Mirfin-Veitch (2005) contends that the closing down of large institutions in Western countries across the world can be attributed to three main factors, although there are others. The first of these was a response to revelations about living conditions experienced in

institutions. The second factor was the emergence of the concepts of normalisation and, later, SRV, as discussed in the previous section. The third factor in the move to deinstitutionalisation was the development of community-based service systems (Mansell & Ericsson, 1996). In New Zealand, the first voluntary community day services were started by the Wellington After-Care Association in the late 1920s, and the first community services with paid staff were begun by the IHC in 1953. IHC services – renamed IDEA in 2005 – expanded from these small beginnings to become a large provider of community residential and vocational services. Other community-based service providers established residential and vocational services for people with learning disability, ranging in size from small one-to-two house trusts to large organisations.

Bigby and Fyffe (2006) have argued that deinstitutionalisation required more than the closure of large-scale institutions and redevelopment of smaller-scale houses. Community-based services have often failed to deliver expected outcomes in terms of social relationships and community inclusion (Young, Sigafoos, Suttie, Ashman, & Grevell, 1998), personal choice (Emerson & Hatton, 1996) and valued social roles (O'Brien, Thesing, Tuck & Capie, 2001). The New Zealand National Health Committee's (2003) review of the lives of people with learning disability found that services were often prescriptive and restrictive in ways that denied people opportunities to achieve "ordinary" life goals. Again, the rhetoric of "ordinary" is used by policymakers without fully considering what it means – a point I revisit in this thesis. While it has been assumed that deinstitutionalised models of service represent a shift from a more coercive model to a one that takes account of the rights of individuals, the work performed by staff in group homes is reflected in the "work" of residents to become more independent (Levinson 2005, p. 57). Thus, people with learning disability were not recipients of autonomy and independence; they were still under the influence of a contemporary liberal society that acted to authorise the conditioning of the normalised independent person.

The physical result of deinstitutionalisation has been the housing of most people with learning disability in the community through the policy directions of community integration and participation. How successful this shift has been for people with learning disability is discussed in the following sections.

Community participation

The campaigning by parent groups and organisations, coupled with the fiscal crisis, contributed greatly to the developments in policy in most Western countries known as “community care.” Large institutions had been discredited, and inclusion in the community was now regarded as the most suitable way for people to live (Johnson and Walmsley with Wolfe, 2010, p. 89). The advent of community care provided for a complex political, economic and social landscape. A critical question, however, is whether this move from institution to the community has meant more than just a change in physical location. The evidence clearly demonstrates that it was extremely successful in physically relocating people with learning disability into the community, yet community living for people with learning disability was then characterised by loneliness and isolation (Chenoweth, 2000). The social networks of people with learning disability when measured post-deinstitutionalisation by Chenoweth were comprised largely of paid support workers and other people with learning disability.

The deinstitutionalisation process envisaged a life in the community that would include employment and housing opportunities; health and human services; leisure activities; and other opportunities as “active” members of the community. Johnson and Walmsley with Wolfe (2010, p. 90) comment that “in some respects the ideas and idealism of activists has been made to serve the baser interests of politicians to cut costs and reduce dependence on the welfare agencies.” The work of voluntary groups, as well as academics like Tizard, in the United Kingdom during the late 1950s and 1960s demonstrated that institutional care was an unsuitable environment and that people with learning disability could be meaningfully employed with the right support and training. This was an important turning point in promoting work as a desirable goal, alongside the recognition in the 1970s and 1980s in many Western countries that children with learning disability were capable of learning and therefore required educating in schools, albeit segregated special schools. This raised the profile of children and young people who up until then had been segregated in what were commonly called junior and adult training centres.

Many more people with learning disability were now located physically in the community, but they were still living a form of parallel existence in which integration was the prevailing

social policy. Opportunities to exercise their civil rights and to explore their agency in a welcoming community environment were scarce. What remains an issue is that the material and social relations of people with learning disability are not analysed and discussed in such a way as to promote solutions. In a consideration of people's networks, the first element of analysis should be the political economy in which the social relationships take place. This would suggest that it is not the person's learning disability that governs their success in establishing and, importantly, maintaining social contacts, but the degree of material support. Material issues such as whether the person can use public transport, has a car and owns a mobile phone have been shown to be important to sustainable social networks. The reality is likely to have been that the policymakers and bureaucrats involved in the move to close down institutions and place people in the community did not consider how to design a system of support for meaningful participation; rather, they were governed by fiscal matters (Chenoweth, 2000, p. 93). Therefore, community participation for people with learning disability would have been little more than community placement.

The influence of “quality of life”

Whereas normalisation and SRV emphasised the importance of people with learning disability fitting within the regimes of normalcy, quality of life (QoL) emphasised inclusion, empowerment and natural supports (Schalock, 1994). Arguably, QoL was a progression in ways of thinking about learning disability in making the connection between individual subjectivity and material conditions. However, the agency still remained with the professional to alter these material conditions. QoL thinking produced a range of approaches to measure and design programmes founded on “well-being.” Such approaches have included opportunities to fulfil one's potential and generate feelings of positive social involvement (Schalock, 1990); programmatic intervention (Brown, 1988); community adjustment (Halpern et al., 1986); productivity (Cummins, 1992); lifestyle (Harner & Heal, 1993); social integration (Larson & Lankin, 1991); and programme improvement and outcome evaluation (Schalock, 1990).

O'Brien (1987) designed the Personal Futures Programme based on five domains that contribute to the QoL of people with learning disability: presence, choice, competence, respect and community participation. These domains can be seen to reflect the language of

consumerism and individualism, as human and health services began to adopt a more corporate approach. These domain terms are still widely used in education policy in New Zealand. By linking the achievement of quality outcomes to the provision of empowering environments, QoL shores up the role of the professional as advocate and promotes empowerment as a professional practice within the learning disability field. This relationship, however, is made problematic by QoL's utilising the language of choice and rights.

The QoL approach in New Zealand marked a move toward recognising and exploring the subjective experiences of people with learning disability and their improvement through empowerment. However, policies still reflected a service funding-orientated position that minimised difference rather than eliminated the material, social and cultural barriers to a sense of belonging for people with learning disability. QoL has been identified as reinforcing the language and practices of corporatism and managerialism in social policy and service provision. In a corporate discourse, the focus remains on "disability" as a management issue. Fulcher (1989) noted the emergence of a corporate-managerial discourse in Western governments alongside neoliberalism twenty years ago. Since the devolution of New Zealand's education system, in line with neoliberal philosophies, there has been a focus in government and Ministry of Education initiatives on mechanisms and systems that allocate and distribute resources (Ministry of Education, 1996; New Zealand Government, 2010). A managerial discourse has taken precedence in New Zealand government reforms in education and special education, at the expense of concerns about human rights and research evidence that supports fully inclusive education (Ministry of Education, 1996; New Zealand Government, 2010). In line with a managerial discourse, New Zealand government responses to the education of learners with special needs has primarily focused on allocating, distributing, monitoring and managing resources (Millar & Morton, 2007; Wylie, 2000). Professionals providing services to people with disability have thrived throughout the Western world in a technicist-managerial climate (Fulcher, 1989; Slee, 1997; Thomas & Loxley, 2001).

This marketisation of human services marked the beginning of neoliberal government policies that promoted normalised individualism, the contracting management of the public sector and the privatisation of public services. The marketisation of human services has resulted in widely differing service provision. The market and community now delivers

services that were formally run by the state. QoL and marketisation have privileged the expertise of the professional and increases inequality while relying on largely unskilled, low paid support workers for service delivery. Community members have become customers and consumers, at the expense of a sense of community belonging. Importantly, this situation has been presented under the guise of choice and empowerment. QoL, then, has not supported the promotion of the voices of people with learning disability but rather abused the language of empowerment while delivering a structure that privileges professional expertise in the pursuit of “normal.”

Community, independence, individualised funding and the market

The recent history of social responses to learning disability has led us to where we are today. Care in the community in many of today’s Western societies adhering to political agendas with their “new right” position and individualistic interpretations of welfare reform and neoliberalism. Under this regime, care in the community is provided to individuals who then have an obligation to participate through sanctioned activities. In response, service design and delivery focuses on the development of competence and independence. These competencies can be interpreted as Foucault’s (1988) terms as “technologies of the self,” seen in neoliberalism through the promotion of “normal” competent citizens.

Paid employment is seen as a passage to participation in modern Western societies and its interplay between productive worker and rampant consumerist. This leaves people with learning disability in a precarious position because of deeply embedded views about their capacity and capability to actively and meaningfully participate in employment. The result has been mostly welfare dependency, symptomatic of the corporatism in human services on the one hand and exploitation, poverty and little meaningful opportunity or purpose in life for people with learning disability on the other (Simpson, 1999).

It was the perceived failure of community care-based programmes that led to market-based individualised solutions being promoted by governments across many Western countries, including New Zealand, at the turn of the 21st century. This resulted in governments promoting “personalised” or “individualised” services, terms which describe a model of support that moves purchasing power from service delivery agencies to individual users and

their families (Duffy, 2006). This shift was expected to facilitate choice, control and the transfer of employment from agencies to individuals, enabling transformation from a service-dominated to a user-responsive service situation (Johnson & Walmsley with Wolfe, 2010). Johnson and Walmsley with Wolfe (2010), for example, have described Duffy's vision of integrated holistic services that support independent living, where resources are better utilised and concentrated without the waste of bureaucratic costs on people's daily lives. Unusually, people with learning disability were at the forefront of this individualised budget implementation in the United Kingdom, which was adopted as Department of Health policy in 2007. Recently, in New Zealand, there has been much interest in how these new models of support – which desire to hand more choice and control to people with disability – can be successful in building a good life. The Ministry of Health has been prominent in this work in New Zealand. These forms of self-directed support allow for the individual to control the resources allocated to them and therefore allow for better use of community resources. Duffy's argument was that self-directed support would pave the way for people to play a fuller part in the community and gain a greater sense of belonging. This would occur by enabling people with learning disability to not only contribute to the acquisition of resources but also consume them, allowing for the creation of employment, volunteering and other socially useful activities (Johnson & Walmsley with Wolfe, 2010, p. 95).

This form of individualised or personalised model is currently being tested in New Zealand. As the result of a recent review of Individualised Funding (IF), completed in 2008 and endorsed by the *Government Response to the Report of the Social Services Select Committee on its Inquiry into the Quality of Care and Services Provision for People with Disabilities* (Ministry of Health, 2009), the Ministry is now working to extend IF and increase the number of providers.

However, changing the economic power base does not necessarily remove the requirement for negotiation over the nature of the relationships between support providers and the user. It is more than about finding a technology or person that makes up for the impairment. A good deal of personalised, consumer directed or user-controlled models being implemented today – like individualised or direct payments, personal assistants and self-advocacy support roles – originated from supporting people with physical disability and were then transferred to people with learning disability. There is little empirical research that explores the success of

these models for people with learning disability (Johnson & Walmsley with Wolfe, 2010, p. 161). For people with physical disability, personal support roles are generally used as purely technical support or “instrument” in order to carry out a range of practical tasks. For people with learning disability, a deeper endeavour is required by personal assistants in terms of the relational dimension in order to fully understand and provide the desired support. For assistants of people with physical disability, “being someone’s hands” becomes the dominant metaphor. If we extend this metaphor further for people with learning disability, the personal assistant might become “the brain of the person” (Johnson & Walmsley with Wolfe, 2010). This leads us into dangerous terrain and underlines the potential for misuse in this form of service provider/user relationship. The depth and motivations of the interactions between people with learning disability and those without might provide opportunities for a deeper, more personal and mutual understanding. This recognition of interdependency has the potential to blur the labels of teacher/student, service provider/service user, client/personal assistant and so on. These relationships can instead become about “you and me,” for who we are and the value we each bring to the interaction can be found in recognition of our relative interdependency.

I have described the recent historical influences that continue to impact on young people with learning disability leaving school today. The current situation for young people with learning disability leaving school in New Zealand is a policy and service landscape that is premised on the language of choice, presence, participation and independence, yet one in which professionals still largely maintain control over the key aspects of their lives. This rhetorical language provides significant challenges for students with learning disability. The recent history of social approaches to the management of learning disability has left young people with learning disability and their families still heavily influenced by the dominant knowledge and practices of specialist services industries and their professionals. Johnson and Walmsley with Wolfe (2010) sum up the situation:

The history of the past century indicates that intellectual disability has been, and continues to be, seen as a social problem. Faith has been placed in structural solutions to a perceived perennial social problem rather than focusing on what people might regard as a good life. Each successive phase is premised on discrediting the past and dismissing its solutions as misguided; “we know better.” Yet there are constants. Families are constant, as is the desire to reduce costs, and,

most importantly for our purpose, are the views imposed by others with regard to how people should live. And the challenge of finding and nurturing a workforce to deliver these different solutions has been consistently underestimated and underfunded. (pp. 98–99)

In outlining these key developments, I have noted the progress made in improving the social and material conditions of people with learning disability. However, these developments still retain oppressive discourses that continue to marginalise, stigmatise and problematise learning disability as an individual cognitive and social deficit. This has characterised the special education and social welfare service systems response. The dominance of professional expertise continues to create issues of rights and citizenship. This landscape provides a troubling backdrop for students with learning disability coming out of schools and problematises their search for a good life. In Chapter 3 of this thesis, I will focus on theorising disability to provide a background to underpin my methodology.

CHAPTER 3: THEORISING DISABILITY

In this chapter, I outline the theoretical frameworks that I have drawn from for my interpretation and analysis of the research data. I examine the ways in which social constructionist and interpretivist epistemologies and theories are relevant to a consideration of how learning disability is constructed and experienced. I develop a rationale for the utility of theory that promotes an interpretative, critical, reflexive approach and draws from a range of perspectives to explore and examine the social construction of disability and the lived experiences of young people with learning disability.

Slee (1997) suggests a methodology that uses many theories and approaches as “tools for thinking.” I argue that this allows a more sophisticated interpretation of the co-researchers and participants’ narratives and experiences in truly opening up what we can learn from the interplay. My theoretical approach is located within a framework of social constructionist, interpretivist, critical and emancipatory paradigms. Social constructionism and interpretivism view knowledge as the outcome of cultural, relational, and subjective processes of meaning-making (Slee, 1997). Knowledge, though always provisional, becomes an outcome of interpretation, negotiation and co-construction. Thus, relationships in all forms become important to an understanding of learning disability.

I examine social, cultural and political theorising from a disability studies perspective. I use critical theory and the work of two critical theorists: Foucault, for an exploration of truth, power and knowledge, and Freire for his powerful critique of education and his championship of a humanising, relational and democratic response. I critique special education knowledge regarding the theoretical and epistemological approaches I discuss. In this way, I reject theory and practice that promotes deficit, individualised conceptions of disability and impairment. I reject the contemporary Western drive for the “autonomous individual” and use Zygmunt Bauman’s sociological thinking and powerful use of metaphors to critique and explore the impact of the market, consumerism, globalisation and “liquid modern” society on the lives of young people with learning disability. Bauman’s sociology of “the stranger” and his critiques of individualism, inequality and moral indifference are powerful themes in his sociological thought. This theorising is what allowed me to define the methodology utilised for the study.

Approaches to theorising disability

The landscape of disability studies has developed over the last 30 to 40 years in response to a growing social, political and intellectual re-evaluation of the situation of people with disability (Meekosha 2004, p. 3). The voice of people with disability is critical to this movement. The origins of this paradigm emerged from critiques by disabled academics such as Finkelstein (1980), Oliver (1990) and Barnes (1991), in the British context, and Zola (1982), Hahn (1985) and Longmore (1985) in the American context. Academics with disability began to reinterpret disability as a dimension of social difference and identity. Because the voices of people with disability had been largely absent, it is pertinent to consider to what extent people with learning disability are represented within disability studies, providing a gauge for the ability of the paradigm to embrace those at both the centre and at the margins of its representation.

Thematically, much of the work disability studies has applicability to learning disability. However, contemporary disability theorists have largely failed to consider learning disability as a unique form of embodiment (Walmsley 1997; Chappell 1998; Goodley 2001; Chappell et al., 2001). Western worldviews have been dominant. I have chosen to explore the British approach, as its theorists have been more explicit in their acknowledgement of the distinctions between the biological realm and the social or material. In addition, my professional experience working with young people with learning disability was mostly gained working in the United Kingdom.

Individual models of disability

Individual models of disability, based on a functionalist view of the social system, have had a major influence on disability studies since the beginning of the twentieth-century. Functionalism, as identified in the work of Emile Durkheim (1857–1917) and Talcott Parsons (1951), defines a sociological perspective that places society as a totalising system that is the sum of its parts. It assumes that these parts perform in particular ways to survive. A focus on the normal and abnormal body is central to the functionalist approach, meaning that disability is conceptualised as a functional limitation of the individual. Thus, with respect to learning disability, this approach has constructed discourses of sub-humanity, demonisation,

medicalisation and deviancy. These discourses have resulted in the individual being categorised as a victim of disability. This “personal tragedy model” then requires their care and protection. In doing so, it legitimises special education and social welfare approaches designed to help people cope with or adjust to their disability (Oliver, 1990; Finkelstein, 1993). From this perspective, the solution to the individual’s problem lies in intervention by a multitude of medical, psychology, rehabilitation and special education professionals, who are charged with diagnosis and with devising regimes of treatment and instruction to cure or reduce the individual’s impairments. This has been termed the “medical model of disability” (Oliver, 1990).

Individual and functionalist models of disability were highlighted within international disability discourse by the World Health Organisation, which in 1980 introduced the International Classification of Impairments, Disabilities and Handicaps (ICIDH) as a tool for classifying the consequences of diseases and their implications. Sustained criticisms from the newly established discipline of disability studies led to a revised classification system, known as the International Classification of Functioning Disability and Health (ICF), which conceptualised disablement as an interaction between the intrinsic features of the individual and that person’s social and physical environment (Bickenbach, Somnath, Badley, & Ustun, 1999, p. 1183). However, despite this recognition of the social sphere, the overall project of the ICF can be seen as an attempt by the scientific world to build and maintain a closely defined and globally controlled biomedical vocabulary. This restrictive model of disability resulted in segregation, institutionalisation and dubious therapeutic, medical and special education interventions, and approaches to social management retained individualised in/competence as the focus for remediation. For people with learning disability, being competent was the sole requirement in the pursuit of participation and empowerment, ignoring material relations and individualisation.

In response, however, a critical approach emerged which explored disability as a major and neglected area of human social experience (Shakespeare, 1998, p. 1). Individual approaches began to give way to an understanding of the socially mediated nature of the disability experience with an emphasis on access and inclusion – particularly for people with physical and sensory impairments, but with arguably relatively little attention for those with learning disability.

The social model of disability

The social model of disability is defined by its political stance, in direct opposition to the individualist medical model of disability. A central element of the social model has been a focus on promoting the voices of people with disability in contemporary society. The medical model was claimed to reduce disability to impairment, so that disability was located within the body or mind of the individual. In this way, the power to define, control and treat people with disability was located in medical and paramedical professions (Humphries, 2000, p. 63). These professions were accused by proponents of the social model of maintaining material and political segregation. In contrast, supporters of the social model were engaged in redefining disability in terms of a disabling environment; promoting people with disability as citizens with rights; and recasting the responsibilities for creating, sustaining and overcoming disablism.

The “medical model” has been defined by British and other disabled activists and researchers over the last 40 years as the polar opposite to the social model (Shakespeare, 2006). Shakespeare has argued that the social model/medical model distinction became the defining characteristic of disability studies in the United Kingdom, ignoring the fact that rejection of the dominance of medical approaches or medical professionals was, as he described, “hardly new” (p. 14). He suggested that in fact, “no authors have ever explicitly affiliated themselves to this medical model” (p. 15).

However, the Union of the Physically Impaired Against Segregation (UPAIS) and the Disability Alliance (1976), made the following statement, which clearly defines the basis from which the social model emerged:

In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairment by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society.

Thus we define impairment as lacking part or part of a limb, organ or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account or little account of people who have physical impairments and thus excludes them from participation

in the mainstream of social activities. Physical impairment is therefore a particular form of social oppression. (p. 14)

This distinction, then, is embedded in social constructionism as the philosophical foundation of the social model. Social constructionism has been criticised for not taking into account the experiential and cultural aspects of disability – for example, the embodiment of pain. Pain itself is generated by a complex relationship between physiological, psychological and socio-cultural factors, and so the individual experience can never be separated from the social context.

The social model is a concept that acknowledges that some individuals have physical, sensory or psychological differences that can affect their ability to function in society. However, the social model suggests that it is society that causes the individual with these physical, sensory or psychological differences to be disabled. In other words, individuals with impairments are not disabled by their impairments but by the barriers that exist in society, which does not consider their needs. The early British approach to conceptualising disability drew heavily on materialist theory and suggested that disability and dependence were the social creation of a particular type of social formation, industrial capitalism (Abberley, 1987). This discourse was mainly concerned with material factors, social relations and political power.

Disability as social oppression was an interpretation promoted by several disabled academics in the United Kingdom, including Finkelstein (1980, 1981), Barnes (1991) and Oliver (1990, 1996). Their social model of disability contrasted with traditional conceptualisations that located the problem of disability in the impaired individual. It contained the following key claims: that people with disability are an oppressed social group; that there is a distinction between the impairments people have and the oppression they experience; and that disability is defined in the form of social oppression, not the form of impairment (Shakespeare & Watson 2001, p. 10). The social model is primarily concerned with the political project of emancipation and, in some of its interpretations, with the development of an oppositional politics of identity (Corker & Shakespeare 2002, p. 3). Since the early 1990s, critiques emerging mostly from feminist and postmodern perspectives have questioned these early materialist approaches, suggesting limits or problems which are associated with underdeveloped application (Thomas, 1999, p. 24). In addition, these critiques claim that the

Western world has largely ignored the “developing” nation’s position and experiences while promoting “first world” capitalism.

Some academics have argued that the social model’s focus on socio-structural barriers downplays the cultural and experiential dimensions of disability (Shildrick & Price, 1996; Corker & French, 1999). Others have argued that the social model largely excluded the experiences of particular groups of people with disability on the basis of gender (Meekosha, 1998); sexuality (Corbett, 1994; Shakespeare et al., 1996; Shakespeare, 1997); race or ethnicity (Vernon, 1999); and age, including both older people with disability and disabled children (Zarb & Oliver, 1993; Robinson & Stalker, 1998). A central issue has been the tendency of social model conceptualisations to ignore the importance of impairment, either in disability theory or in terms of its impact on the lives of people with disability (French, 1993; Crow, 1996). Shakespeare (2006) provided a comprehensive critique of the social model with respect to its reluctance to embrace impairment and recognise the dynamic relationship between disability and impairment. His claims were premised on the view that there can be no impairment without society, nor disability without impairment (p. 34). Shakespeare illustrated this position by claiming that “first, it is necessary to have impairment to experience disabling barriers ... Secondly, impairments are often caused by social arrangements ... Third, what counts as impairment is a social judgement” (p. 35). He suggested that the disability rights movement has always championed inclusive provision and a world free of barriers. He comments that “the reason for barrier removal is to facilitate the participation and improve the quality of life of people with impairment” (p. 50). Barrier removal and inclusive provision may be the most appropriate way of achieving this aim and developing stronger links between people with and without disability. This is a very complex process, reliant on a range of factors that are themselves unstable. Shakespeare went on to say that for people with learning disability, there might be occasions when alternative provision were more appropriate to realise their goals, as with supported employment or alternatives to employment that provided the person with a purpose, value and fulfilment in life.

Ongoing critique of the social model has come from those who have argued that the interests of people who have particular forms of impairment are not particularly well served or are underrepresented by the social model because their experiences do not “fit” the model (Thomas, 1999, p. 101). These include experiences of Deaf people (Corker, 1993), people

with psychiatric impairments (Beresford, 2000) and, of primary interest in this thesis, people with learning disability (Chappell, 1998; Chappell et al., 2001; Walmsley, 1997; Goodley, 1997, 2000, 2001). This line of argument has opened up the possibility for the examination of the experience of learning disability as a particular form of embodiment, and it has resulted in an important area of debate within disability studies. Developments in the field more generally have further problematised the notion that impairment is at least partially socially produced (Hughes & Paterson, 1997; Thomas, 1999) and therefore experienced in specific ways for different people, at different times and in different locations (Shuttleworth & Kasnitz, 2005). These theoretical developments are important to the conceptualisation of learning disability because they encourage deeper understanding. In this thesis, I adopt a “best fit” theoretical approach that acknowledges changing perspectives and promotes the lived experiences and narratives of the co-researchers and research participants (Bogdan & Biklen, 1992).

Learning disability and the social model

While it is important to recognise achievements, it is necessary also to raise concerns about the direction of some of the debates in the sociology of disability and point to new pathways for debate. Much of the content of this chapter has been shaped by a sense of frustration at the continued exclusion of people with intellectual disabilities from the analyses of the sociology of disability. They are located currently in the backwaters of the sociology of disability studies. Their experiences and aspirations should take their rightful place in the mainstream of debates about disability. (Chappell, 1998, p. 219)

Chappell made these comments at the end of the 20th century, but I would argue that we still have a long way to go in establishing a framework that critically examines and meaningfully engages with young people with learning disability and their education, life experiences and aspirations. There is a lack of detailed descriptions of the practical application of methodologies, and there are few honest accounts of the many challenges involved. This thesis is an attempt to respond positively to that gap.

The social model’s central belief that disability is socially constructed provides a political and social strategy, specifically the removal of barriers in the physical and social world. Social model interpretations have particular relevance for the continuing exclusion of people with

learning disability from employment and education. Exclusion from participation in the world of information and knowledge due to language and communication barriers is another example. Barriers such as the style and pace of communications in the 21st century might work against those who require extra time to process verbal and written information (Shakespeare, 2006). Additionally, access to communication and information technologies such as mobile telephones and the Internet are more often than not governed by material conditions. This might mean exclusion for many people with learning disability whose lives tend to be dominated by low socio-economic status. Exclusion in this sense has direct, identifiable and disabling consequences for some people with learning disability. My experience is this form of exclusion is more prevalent among those with more profound and multiple impairments, although not exclusively so. Interestingly, as described in the findings chapters of this thesis, information technology became a useful tool among members of the research team for communicating in a variety of ways – thus enhancing the status and influence of my co-researchers with learning disability, problematising simplistic interpretations and signposting a more sophisticated response to what is a dynamic and complex environment.

The social model supports people with learning disability in enabling the identification of specific barriers and related needs, such as accessible information, politically sensitive support and committed allies and supporters. Importantly, this kind of thinking also allows recognition that barriers are not only socio-structural but also socio-cultural. This enables the expansion of the notion of access beyond the physical or structural, towards a notion of inclusiveness in a cultural sense. This conception is useful in understanding the personal and cultural motivations of politically active people with learning disability, who seek moral recognition and social presence as much as the removal of material, organisational and social barriers. Self-advocacy movements, and in the New Zealand context, the People First movement have typified this overt drive for greater influence over and voice in political agendas.

One of the most important features of the social model has been the relevance of personal history and the lived experience (Chappell 1998, p. 217). First person and life experience accounts have provided the underlying framework for the development of insights into the meaning of disability (Oliver 1990; Abberley, 1987, 1993, 1996). Life stories have

highlighted the subjective experiences of impairment and the personal and political visions for an inclusive society (Campbell & Oliver 1996). Critical disability studies has resulted in a number of accounts that explore the experience of learning disability by such people and their advocates (see, for instance, Bogdan & Taylor, 1976, 1982; Booth & Booth, 1994; Goodley 2000).

There has been a tendency to “add in” intellectual impairment or assume its implicit inclusion that has resulted in claims that the social model refers to all people with disability, when it can be argued it does not (Chappell, 1998, p. 214). I note that the personal stories of people with learning disability have tended to be neglected in the development of the social model, while personal lived experiences of impairment have been “quarantined” from the British social model.

Socio-cultural approaches to learning disability

Socio-cultural approaches provide an opportunity to tackle the social model’s neglect of the lived experience of people with learning disability. In considering whether the social model has the capacity for engaging with the experience of learning disability, debates regarding the socio-cultural nature of impairment and its relationship to the experience of disability are important. If impairment is culturally and socially produced, it is possible that many people with cognitive impairments will not be aware that they are impaired – and if one is not aware of one’s impairment, is one in fact impaired at all? Only when the socio-cultural experience of impairment meets with processes that negatively value it does the experience of disability become overt in an individual’s life. Awareness, then, becomes important in the socio-cultural construction of impairment, in that recognising impairment means making comparisons with other people and as such is pertinent to the study of learning disability. Crucially, people with learning disability are an extremely heterogeneous group and are diverse in their levels of impairment and therefore consciousness. It is thus extremely difficult in some cases to make valid judgments and interpretations regarding people with learning disability.

It is important to acknowledge that this study engaged the views of people who have been mostly labelled with moderate to severe learning disability, not those with more profound and

multiple impairments. A socio-cultural context is pertinent to consider here, as it is a space that respects and promotes difference; it does not see difference negatively but instead celebrates the unique difference of all. This celebration of difference allows for reframing of the lived experience of learning disability, and learning disability can therefore be seen as a unique form of embodiment. However, discomfort about difference is sometimes expressed as hostility and fear toward the existence of people viewed as “damaged” or “imperfect” (Oliver, 1990). Beliefs that position people with learning disability as “tragic others” are often expressed through patronising attitudes, pity, embarrassment, discomfort, over-protection and fear of difference (Barton, 1996).

In analysing students with learning disability and their understandings of a good life as they transition from school, this study positions such socio-cultural considerations as important. The majority of young people with learning disability in this study actively resisted being “disabled” by entering a socio-cultural space that values difference and not deviancy. If we accept the notion of difference, then we can imagine a repositioning of the material, social and cultural lived experience of young people with learning disability. This will test the landscape for social model supporters, who may view themselves as oppressed and therefore in opposition to the socio-cultural position. Valuing difference is important, particularly on a political level, but there needs to be a consideration and acknowledgement of how it manifests itself across impairment groups. One particular experience of impairment may be problematic when measured against the disability movement’s drive for “individual autonomy.”

Another issue that Shakespeare (2006) recognises is the difficulty of identity and impairment; as mentioned earlier, the reality is that some people labelled with impairment do not consider themselves as disabled. Equally, those who acknowledge their disability may reject how others perceive the nature of their impairment. Issues of difference and identity are therefore contentious. Socio-cultural theorists may only engage so far in the life worlds of those more intellectually impaired people, because while accepting their very humanness is the first step, we must continue to question the notions on which we base our understanding of what personhood is as meaningful behaviour and interaction.

In order to gain any insight into such people's lives, and to comprehend how they understand and maintain meaningful relations with others, people with learning disability's particular actions and behaviours must be acknowledged and engaged with as legitimate, meaningful and purposeful. Rather than viewing conformity to normative social practices and behaviours as the means for their social inclusion, this acknowledgment and engagement should be recognised as the fundamental basis for people with learning disability's very sociality. The theoretical and methodological tools that are required to understand and engage with these life worlds, however, are not those generally used by socio-cultural theorists. The focus on labels, constructs, structures and meanings can allow for understanding the impact of socio-cultural practices and attitudes; however, it do not allow us to actually enter into these people's worlds and relate to them as individuals who are already fully human and encultured beings.

This thesis, therefore, describes a research project that embraced the requirement for a relational, reciprocal, interdependent approach that provided knowledge for a shared search for a good life. A positive way forward is to bring together the notions of celebrating difference, diversity and respect with ideas of disability and impairment as equally socio-cultural. Goodley (2000) describes this as being about breaking the social model creation of a rigid connection between intellectual impairment (biological/bodily) and learning disability (social/cultural).

I have attempted to illustrate the socio-cultural nature of impairment and disability and its complex and contested landscape. This leads me on to a discussion of conceptualisations of the body and embodiment, particularly in relation to feminism, queer theory and postmodern social theory.

The embodied form of learning disability

In recent years, there has been a growing interest by sociological researchers in the cultural representation of disability and the disabled body (Shakespeare, 1997). This can be seen in the work of feminist writers, queer theorists and postmodern social theorists. They position the human body as biological but also socially constructed by discourses and social practices. Meekosha (1998, p. 163) explores contemporary difference theory in her critique of the body

in the social world and offers an alternative framework for the complex and multiple dimensions and processes involved in disabled embodiment. Meekosha moves beyond binary narratives of nature/culture, body/mind and impairment/disability. For those born as “other,” gendered and disabled bodies are fundamental to contemporary social analysis, as they offer an opportunity for examining the contradictions of social, political and psychological discourses. Foucault’s works (1979, 1982, 1988) were influential in relation to the disabled body, as he examines the regulation, surveillance, discipline and control of difference to develop a greater understanding of how social attitudes and processes construct types of bodily and cognitive difference.

Feminists have explored the impact of patriarchy as determining social attitudes which characterise women as weak, irrational and unpredictable, rejecting the assumption they are defined by their biology (Meekosha, 1998). Placing disability studies in a feminist context implicates feminist theory’s inquiries into gender as a category; the body’s role in identity; and how social power relations impact an analysis of disability. A good deal of this sociological inquiry in disability is grounded in the social institutions, beliefs and value systems of capitalism, which produced the globalisation of industrialisation, mass surveillance and technological warfare in Western society. This modernity is based on the narratives of binary thought (Corker & Shakespeare, 2002). In direct opposition to this, postmodernism has challenged the belief in a single reality or truth, promoting instead multiple realities and difference. Postmodernism has supported the critical study of disability through bringing new perspectives to the examination and exploration of social inequalities and privileging power in relation to disability, gender, race and ethnicity, class, sexuality and age. These new perspectives seek to understand dimensions of knowledge and culture, not just material factors. The social aspect of knowledge allows for an exploration of learning disability as an experience of embodied social relations. It then becomes appropriate to conceptualise people with learning disability as experiencing, understanding and interpreting their world in unique ways. This allows us to establish how these people “speak” in multiple voices from a social, cultural and political space (Douse, 2009).

A focus on the body provides a vehicle for examining the interactions of mental, physical and cultural phenomena in its production. Thus, intellectual impairment and disability as constructs arise in the context of social processes that form identity. This can open up

examination of the ways that people with learning disability might live in their bodies (Corker & Shakespeare, 2002, p. 10). Combining the notions of embodiment and difference is useful in advancing beyond traditional ideas about social, political and cultural participation for people with learning disability. Focusing on the social mechanisms rather than the biological differences that cause bodies to be recognised as different in relation to socially privileged qualities enables critical disability studies to explore and define the cultural means by which differences become negatively invested (Shuttleworth & Kasnitz, 2005). When considering young people with learning disability, this negative emphasis is seen in the primacy of independence and competency and their binary opposites, which characterises social responses to and judgements about them. What is important here is the questioning of how bodies became labelled with differences, which were then taken to be ontological differences. Differences as well as commonalities must be respected for those people who have historically been excluded and whose voice is too often silent, as is the case for young people with learning disability.

Knowledge, power and resistance

I now consider how the dynamic relationship between knowledge, power and resistance influences the lives of young people with learning disability. In the last sections, I explored theoretical approaches to learning disability, and I now combine these ideas to examine the relationship between power, knowledge and resistance. Foucault's work has enabled us to acknowledge that discussions of knowledge raise questions of power that are ever present. He defines power as a relationship between two agents capable of action, where one agent affects the possibilities of another's actions (Foucault, 1980, 1988). Thus, every social relation involves power, which is always shaped by individuals and institutions. In Foucault's definition of power, there is opportunity for resistance, because if there are myriad points of power there can be myriad points of resistance.

Foucault's development of poststructuralist analysis of the body allows us to move away from binary oppositions and see the notion of meanings and intellectual categories as shifting, fluid and unstable (Foucault, 1978). In *The History of Sexuality* (1978), he showed how power is deployed as directly connected to the body through an analysis in which the biological and the historical overlap in an increasingly complex manner in line with the

development of modern technologies of power with life as its objective (p. 151). This allows us to see the social construction of the disabled body through the ongoing procedures of both internal and external disciplinary power. This conceptualisation views modern power as non-authoritarian, while producing and normalising bodies to acknowledge relations of dominance and subordination (Bordo, 1993). With respect to the experiences of young people with learning disability in their journey towards a good life, this conceptualisation allows us to see that power is a dynamic network of forces that assume historical forms. In this way prevailing forms of selfhood and subjectivity are maintained through individual self-surveillance and self-correction to norms (Bredo, 1999, p. 253). Foucault called this efficacy of disciplinary practices – as self-generated and self-policed – “technologies of the self.”

According to Foucault (1980), there is an interdependent relationship between the production of systems of knowledge and truth and how power is accrued and exercised. In regard to knowledge, truth and power Foucault said that:

Truth is a thing of this world. It is produced only by virtue of multiple forms of constraint. And it induces regular effects of power. Each society has its regime of truth, its “general politics” of truth: that is, the type of discourse which it accepts and makes function as true; the mechanisms and instances which enable one to distinguish true and false statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who are charged with saying what counts as true. (1980, p. 131)

Foucault suggested that individuals actively participate in their own subjugation through discursive activities and relations. He saw individuals as actively involved in discursive relations of power. In discussing the nature of power and the relationships between power, knowledge and truth production, Foucault said:

If power were never anything but repressive, if it never did anything but to say no, do you really think one would be brought to obey it? What makes power hold good, what makes it accepted, is simply the fact that it doesn’t only weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression. (1980, p. 119)

We can use these conceptualisations by Foucault as supporting an analysis of the experiences of young people with learning disability who are making the turbulent transition from school to post-school life and experiencing the search for a good life. If we consider the disciplinary regimes of bio-medicine and special education alongside notions of consumer-based empowerment and independent living, we establish the contemporary learning-disabled body. Deficiency, incompetency and incapability are not pre-prescribed qualities of the learning-disabled body, but rather function both as norms and as practices of control and regulation that produce the bodies they govern (Shildrick & Price, 1999, p. 432). Postmodern approaches, then, give opportunity to a re-theorisation of social, cultural and political structures and their practices.

In returning to feminist social theory – in particular the work of Brede (1999) – and assigning a feminist conceptualisation of power, we are able to observe that power is not held by anyone specific; rather, people are positioned differently within power structures. Using the analogy of team sport, while no one may control the rules of the game, there is recognition that not all players on the field are equal (Bordo, 1999, p. 253). This not only has particular significance for the research team described in this thesis, but also generally in the struggle to map a meaningful pathway for students with learning disability as they transition from school. Foucault recognises the interrelationship between power and resistance when stating that “there is no power without revolt” (1988, p. 84), implying that the learning-disabled body is never passive in either a physical or social sense. This allows for students with learning disability to be recognised for who they are and what they desire, not only socially and politically but also in terms of a moral and emotional space within which to make their own meanings of life that challenge contemporary assumptions about the kind of life they want.

In exploring sociological perspectives to the study of disability, I have considered different theoretical positions and their implications for an exploration of learning disability. The marginalisation of learning disability by disability studies has begun to be addressed by postmodern/poststructuralist and feminist perspectives that pull together notions of disability, impairment, embodiment and power. The following section now draws on the work of Paulo Freire, his critique of contemporary education systems and calls for democracy as an

educational method and not merely a goal of democratic education. I consider a critical social theory approach because of its emancipatory potential for education and society.

Critical social theory

The term “critical” refers to the exposing, challenging and rejecting of beliefs and practices that limit human freedom, justice and democracy. In Habermasian critical theory, knowledge is “emancipatory.” Habermas (1989) describes this as both the unmasking of ideologies that maintain the status quo by restricting the access of groups to means of gaining knowledge, and the raising of consciousness or awareness about the material conditions that oppress or restrict and taking action to resolve the situation.

Critical social theory’s main goal is the improvement of the human condition. As such, it has much of relevance for this thesis. This philosophical approach to research is fairly different from traditional approaches. Traditional social theorists contribute to maintaining the *status quo*; critical social theorists seek to emancipate people. Critical social theorists are concerned with challenging and finding alternatives to existing social conditions. They assume that all social knowledge is value laden, that all scientific knowledge is a social construction, and that reason and critique are inseparable and reflexive. Critical social theorists not only explore the limitations of different research approaches, but also take a reflective look at the approaches they themselves use. Critical social theorists seek to improve human conditions by critiquing the ideology behind certain styles of research, and also by becoming involved with real life situations where power is manifested with respect to how one conducts human inquiry.

Critical social theory identifies three kinds of inquiry upon which researchers may base their quest for knowledge: technical, practical, and emancipatory. In the technical interest, there is a focus on predicting and controlling the natural and social world. Information technology is often viewed as an instrument for control, and is therefore frequently studied according to the technical interest. The second type of knowledge interest, practical, focuses on human interactions, including traditions, social behaviours and relationships. Its interest is to clarify the meaning of a given situation in order to better understand it. The third category, the emancipatory knowledge interest, is specifically targeted towards the liberation of individuals. It is achieved through discursive action, where the force of the best argument has

the right to change a given situation (Habermas, 1979). Rather than exploring a situation so as to control it (technical interest) or to understand it (practical interest), an emancipatory interest seeks to free people from physical, mental and social injustice. It is this latter interest that best serves the critical social theorist, and so it is my interest – although I acknowledge the influence of the practical.

Freire (1997) viewed education as an opportunist landscape for attending to issues of democracy, social justice and emancipation through a consideration and understanding of the contexts and lived experiences that students and teachers bring to the process. He suggested that respect and recognition of lived experience is fundamental to an emancipatory pedagogy (Freire, 1998). He urged progressive educators to recognise and value the experiences of students in their everyday worlds by engaging with popular culture. Freire's work provides a persuasive argument for combining the theoretical with the practical, in that we must always keep in mind the lived experiences of those excluded or marginalised when we develop solutions (Oliver, 1996; Goodley, 2001).

Freire (1997, 1998) suggested that theorising should begin with commonsense understandings of our social, cultural, economic and political realities. He believed that the ability to think critically and reflexively came from developing and using a keen and creative intellectual curiosity that was capable of self-criticism. In criticising itself, “ingenuous curiosity” becomes “epistemological curiosity,” as through greater methodological precision it appropriates the object of its knowing. Freire argued that to transform society, we must be “ingenuously curious” about how we and others construct meaning through our experiences of living and being situated within particular historical, economic, social, political and cultural contexts. This “knowing” then becomes “epistemological curiosity” in order to transform ourselves and our contexts (Freire, 1998). Epistemological curiosity involves critical thinking and understanding about what we know, how we came to know it and the influences on our relationships with others in society.

My interest in this thesis is in developing and co-constructing knowledge through the collective experience of the co-researchers and participants. In co-interpreting the stories that resulted from the study, I draw on and utilise the “intelligence of experience” with a “critical epistemological curiosity” that constructs reality and interrogates the implications of those

constructions for how students and young people with learning disability are positioned in education and society. Simultaneously, as Carlson (2010) suggests, I must act with “epistemic modesty” in accepting my position as a person without disability, and I must act with “epistemic reflexivity” as suggested by Moss (2005).

Social constructionism

Constructionism has developed over recent decades in the fields of philosophy, history and literary criticism (Crotty, 1998). Husserl’s phenomenology and the critical theory influenced by Marx’s interpretation of the history of ideas have been important influences, as was Berger and Luckman’s (1967) seminal work on *The Social Construction of Reality*. The sociology of knowledge examines the history of ideas and the sociology of contemporary life in order to understand what knowledge is, looking at how it is actually used and how new knowledge is created. Social constructionism, then, offers a useful understanding of what knowledge is and how it is maintained and developed. A social constructionist epistemology assumes that individuals can exercise agency through their participation in the social construction and interpretation of their world.

From a social constructionist perspective, a neutral body of knowledge or interpretation does not exist (Bogdan & Taylor, 1992; Crotty, 1998). Social constructionism seeks shared systems of meaning; as such, it had particular relevance for our participatory study and collaborative venture. It takes a critical stance towards assumed knowledge (Ferguson & Ferguson, 1995). This critical stance can challenge ideological and oppressive uses and practices. It can act to unmask deficit, normalising constructs in its form of rallying call to critical theories. It can provide insights into the construction of particular identities based on characteristics such as sex, race and ability that were once widely considered to be biological, stable and natural states of being (Slee, 1997). From a social constructionist perspective “all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (Crotty, 1998, p. 42). Social constructionism, then, is interested in the contents and effects of particular forms of knowledge and how individuals and groups, as knowledge producers, locate meaning to their

world (Crotty, 1998). Hosking (2002, p. 7) posited a relational constructionism, seeing “all constructed realities and relations, as produced and emergent in relational processes” (p. 7).

From a social constructionist perspective, a person’s ability and disability is the product of the social and not what might be going on inside them (Shotter & Gergen, 1989). Learning disability, then, is not a real, internal condition of the individual but is socially assigned, usually by the “expert” or professional knowledge powerbroker. The effects of this are seen in the special education professional’s perceived position of knowledge and power as “expert” over the young person with learning disability. Knowledge claims are also related to historical and cultural factors. This is evidenced, for example, in the way that discourses of eugenics provided a rationale for the institutionalisation of people with learning disability. Social problems are socially constructed through explanations that legitimise societal claims that people with learning disability are a burden and therefore “other.” The interesting point about the historical context of current social constructions of knowledge is that they are contingent; they are the “current episode” and will change over time. We also create realities about learning disability in our interactions with each other through language (Nunkoosing, 2000, p. 58). This can be seen in the discourses of special education, where these needs can only be met by special educationalists who have the special knowledge to make decisions and arbitrate over who succeeds and who fails.

Social action, understood as constructed in the interrelationship between individuals and their social, political and cultural contexts, has relevance. From interpretivist, socio-cultural and emancipatory perspectives, the narratives and lived experience of the co-researchers and participants in the present study have been critical in constructing and making sense of our collective human reality and action (Ballard, 2003; Freire, 1997, 1998). A social constructionist epistemology assumes that individuals can exercise agency through their participation in the social construction and interpretation of their world (Burr, 1995; Crotty, 1998; Ferguson & Ferguson, 1995). Gergen (1999) points out that social constructionist researchers have differing interests in relation to individuals and society. Rather than creating strict theoretical divisions between the personal and the social, social constructionism focuses on interrelationships. The interrelationship between individual and socio-cultural contexts is what produces meaning, knowledge and reality. Social constructionism, then, is interested in social processes, structures and relationships that are shared rather than individual meaning.

In this research, I have drawn from, social, political and cultural and other theoretical perspectives in order to be aware of more sophisticated views of subjectivity, social construction and action. Social constructionist theory has encouraged me to focus on my relationships with the young people with learning disability, founded on ethical, moral, social justice and democratic concerns. It is a framework that has allowed me to ask different questions in this research, questions that challenge assumptions concerning young people with learning disability.

Challenging dominant cultural assumptions

Challenging dominant cultural assumptions regarding the lived experience of people with learning disability is crucial to their emancipation. These assumptions act to exclude young people with learning disability from education and society. Our study is an exercise in challenging these dominant assumptions concerning people with learning disability. Some of these assumptions are as follows:

- Positioning learning disability as a “problem” for the individual. This encourages society to disassociate responsibility for its construction and its experience. Negative reactions by people without disability are based on negative, uncomfortable and stereotypical beliefs about disability (MacArthur et al., 2000).
- Viewing people with learning disability as victims of a “personal tragedy” who require charity and support from professionals and others in order to come to terms with their position (Goodley, 2001). This can lead to a situation where responses from the individual with disability or their parents are viewed by professionals as evidence of not yet coming to terms with their position (Thomas & Loxley, 2001).
- Positioning the person with learning disability as “other.” This can generate responses of pity, over-protection, patronising behaviour and fear (Barton, 1996; Oliver, 1990). A positioning as “other” or “different” or “not like us” frequently results in segregation, such as separate schooling for people with learning disability (MacArthur et al., 2000).

- Presenting the student's difficulties with learning as being inextricable from their disability. This tends to occur in schools and has been called "ableism" (Bogdan & Biklen, 1977). Bogdan and Biklen (1992) suggest that ableism reinforces negative values on disability and difference and in this way denies the rights and identities of people with disability.
- Defining the person with learning disability's identity wholly by their impairment or disability. This leads to denying the importance of providing time for and a context in which their capabilities can be better understood.

Working from a DSE framework, it is my aim in this thesis to expose, challenge and reject these dominant cultural assumptions that underpin social constructions of disability (Bogdan & Biklen, 1977; Bogdan & Taylor, 1982).

Challenges to special education

Special education knowledge tends to reject its subjective underpinnings and the political and lived effects of its theories and practice (Skrtic, 1991; Slee, 1997). Slee (1997) is vocal in his criticism of special education's assumptions about the "scientific" and "expert" status of its knowledge. Slee rejects the ways that an empiricist, "scientific" discourse is used to portray this knowledge as neutral and unquestionable. Lather (2012, p. 558) uses the term "scientificity," which signifies "an arena of struggle in broadening the definition of science." The term "scientificity" is borrowed by Lather from Foucault's concept and used as a tool for a critical understanding and analysis of education policy and its relationship to practice through a qualitative methodological approach. This allows for the critical consideration of neoliberal education policy I take up in Chapter 6. From a social constructionist perspective, positivist theories tend to ignore relations of power while at the same time exercising that power through controlling and gate-keeping what is known and who can speak or act with authority (Burr, 1995). If we take special education knowledge and look at it through a DSE lens, then we expose the fundamental differences in ethical, political and ideological stances. DSE actively promotes its ideological, political and ethical stance.

A Foucauldian analysis of social institutions positions them as in many ways coercing people to comply with their aims. In this way, a Foucauldian account of social construction could

reveal the needs and requirements of institutions such as special education and social welfare services as to what constitutes learning disability. What constitutes normality, intelligence and other concepts are the tools that perform the work of institutional power. This serves the needs of education and the wider society. For example, special schools and special units on a regular school site segregate students with learning disability from the mainstream of schools, thus making the management of classrooms or the delivery of the curriculum more straightforward and less troublesome. This explanation might also be seen to keep the regular school more “normal” while positioning the special school a “safe haven” for students with learning disability, away from the demands of the mainstream secondary school. This Foucauldian account also supports what I will describe as “special education maintaining its specialness” and therefore allowing the secondary school to abdicate its responsibility for students with learning disability. In this way, the privileging of “expert” knowledge influences the type and form of relationships and pedagogy within schools (Slee, 2001). Teachers, who may have been exposed to a Western psychology-based knowledge paradigm in their teacher training (Skrtic, 1991, 1995; Slee, 2003), often view special education staff as the “experts” about students with learning disability. This means that mainstream teachers will often follow the “expert” guidance of special education staff when working with these students (Slee, 1997).

In addition, special education language and rhetoric such as “inclusion,” “celebrating diversity,” “special educational needs” and “learning disabilities” provide the illusion of inclusion. This circumvents critical reflection about exclusionary deficit discourses and discursive practices (Morton & Gibson, 2003; Slee, 1997, 2003). Labels such as “learning disability” (Sleeter, 1995), “learning difficulty” (Goodley, 2001) and “intellectual disability” (Rapley, 2004) serve political and bureaucratic purposes and reproduce and maintain the dominant social order (Danforth et al., 2006; Slee, 1997).

From a social constructionist perspective, positivist scientific theories and their grand narratives fail to acknowledge relations of power while simultaneously exercising that power through restricting what can be known and who speaks with authority (Burr, 2003). I would argue that the major difference between DSE and special education knowledge is that DSE is overt about its ethical, political and ideological stance, whereas special education knowledge

largely rejects its subjective foundations and the political and lived effects of its theories and practices (Skrtic, 1991; Slee, 2001).

The social thought of Zygmunt Bauman

I now introduce the critical social thought of Zygmunt Bauman to position young people with learning disability within contemporary society. I do so because understandings of young people with learning disability and their transition from school must be located within their experiences of not just education but wider society as well. Bauman's body of work is rarely connected with disability (Hughes, 2002) but I believe his sociological imagination and particularly his use of metaphor to describe and position those people who suffer from inequality or are considered different or "other" in society has much to offer an analysis of young people with learning disability and their lives in transition. I draw on his work because it has relevance in positioning young people with learning disability in contemporary society, particularly regarding their search for a good life. His critique of moral indifference and inequality in society is directly relevant to how people with learning disability are understood.

Bauman's more recent work concerns the many challenges of society in a globalised world where political power is fragmented, social exclusion is rife and class, culture, ethics, consumerism and morality are constantly being reframed and reinterpreted. Bauman wants to understand our potential in a "liquid" modern world and the factors that impact this potential (Tester, 2002). His work is founded on a belief that the world can be a better place. Bauman, like Foucault, is intrigued by the changes affecting capitalism and bureaucratic rationality. They both articulate a position that sees no distinction between scientific and humanistic knowledge. In Bauman's view, all knowledge is humanistic; thus knowledge is praxis and has the potential to understand and importantly transform the world. In the next sections, I introduce those of Bauman's metaphors that have relevance for this thesis.

Bauman and liquid modernity

Order and ambivalence are important themes in Bauman's assessment and interpretation of society in modernity and postmodernity. He uses the metaphor of modernity that is "liquid,"

writing a number of books on the theme that begin with *Liquid Modernity* in 2000. Other books followed: *Liquid Love* (2003), *Liquid Life* (2005), *Liquid Fear* (2006a), *Liquid Times* (2006b) and *Culture in a Liquid Modern World* (2011). Bauman believes we now live in a world of uncertainty, short-term consumer pleasure and weakened communities.

In his book *Liquid Modernity* (2000), Bauman explained the world as fluid and transient, describing “the new lightness and fluidity of the increasingly mobile, slippery, shifty, evasive and fugitive power” (p. 14). He saw this as overcoming the limitations of postmodernism and putting back on track the modern problem of institutional stability (Hughes, 2002). By substituting postmodernity with liquid modernity, Bauman suggested that the modern era is not yet over, and we are not therefore limited to a condition of difference.

For Bauman, modernity has meant celebrating difference in one sense but in the form of embodied self was constituted by social concepts that acted against these same things (Hughes, 2002). Conformity has been seen as the normalising culture that excludes and discriminates against those who are positioned as not “normal,” as with young people labelled with learning disability. To Bauman, modern culture has been the space where moral indifference and heterogeneity meet to eradicate difference. In this way, Bauman believed that the Holocaust was an expected outcome of modernity that could not be understood outside of the cultural, bureaucratic and technical inclinations of its project. Hughes (2002) saw important parallels for scholars of disability studies when recognising that “modernity has found it extremely difficult to accommodate impairment” (p. 576). Hughes considered bureaucracy to have been the perfect vehicle in modernity to distance the unfamiliar or the stranger. However, postmodernity marked a change where difference was promoted and celebrated. The previously invisible became visible through, for example, in the closure of institutions and support in the community. Arguably, this greater visibility made the lives of people without disability more aware of impairment. However, postmodern materialism is rampant in Bauman’s fluid, episodic society and more than ever deeply divides people as those who have and those who do not. This leaves young people with learning disability at risk of not being defined by what they produce or consume. From this standpoint, special education policy and bureaucracy in New Zealand has shown its increasing resilience and ability to exert a controlling influence over the lives of students with learning disability.

In Bauman's (2000, 2003, 2011) view, liquid modernity constructs identities through consumption. This form of identity construction acts to exclude students with learning disability, as they are overwhelmingly consumers of welfare support and can be described as what Bauman has called "flawed consumers." Material possessions and wealth, such as cars, houses and other expensive goods, are assets not usually purchased or owned by people with learning disability because they mostly do not work. Most young people with learning disability will never own a house or car because they are overwhelmingly consumers of an increasingly marketised welfare system. For people without disability, material wealth is usually gained through a working life and paid employment or productive labour. In contrast, young people with learning disability tend to have a future defined by what Mitchell and Snyder (2010) refer to as "non-productive labor" (p. 179). Paid employment, as highlighted, is unusual in any form for people with learning disability, let alone in a form that will provide the means to engage in the pursuit and acquisition of such material possessions. In the current neoliberal, competitive market-based environment in New Zealand, individual wealth and success is mostly reliant on being near the top of the income ladder, where you are free and have more choice. However, freedom and choice is still contingent on maintaining a competitive position in the ever-changing material pursuit that defines contemporary liquid-modern society. I understand this situation in relation to value. Liquid-modern society values some consumption more than others. Welfare consumption, or non-productive labour, is not valued, and this creates identities for young people with learning disability that are perceived as unworthy or flawed. I discuss this further in the upcoming section on flawed consumers.

How students with learning disability can create a valued and purposeful identity within this fluid, individualised environment is an important question in their journey towards a good life. Students and young people with learning disability are largely managed and controlled by special education and social welfare systems that restrict their opportunity to actively participate, let alone belong in this addictive, liquid modern pursuit of happiness. Where does this leave them? In Bauman's (2000, 2004, 2011) view of contemporary liquid society, happiness is precarious, uncertain and premised on individual gratification, competition and material consumerism. This individualised pursuit comes at the expense of meaningful, long-term relationships and a sense of belonging in the community. In this thesis, I develop an

argument that interdependence, reciprocity and being valued for one's contribution and who one is can provide an alternative to moral indifference and competitive individualism.

Bauman's metaphors

"The stranger"

All societies produce strangers ... each kind of society producing its own strangers ... in its own inimitable way. These strangers ... are the people who do not fit the cognitive, moral or aesthetic map of the world. (Bauman, 1997, p. 17)

Bauman has used the metaphor of "the stranger" as a theme in his sociological critique and as a tool for understanding how people are marginalised and excluded. I contend that students with learning disability are largely strangers to mainstream education and society in general. Bauman's focus on the social construction of the stranger and its different forms has featured in much of his work since the 1970s. Recently, it has been evident in his books *Work, Consumerism and the New Poor* (1998a), *Globalization: The Human Consequences* (1998b), *Liquid Modernity* (2000), *Society Under Siege* (2002), *Wasted Lives* (2004) and *Collateral Damage* (2011). For Bauman, modernity is a normalising culture, and his interest is in how social and cultural practices create and negate strangers (Hughes, 2002). In this sense, the cultural response to difference has been premised on the socio-historical responses to the "problem" of learning disability – as, for example, with institutionalisation.

I utilise Bauman's notion of the stranger to emphasise how the workings of social marginalisation and cultural exclusion act against people who are defined as other. Bauman's stranger is defined as being not anybody, but somebody. Everyone is aware of the stranger's existence; otherwise, the stranger would have disappeared into the faceless crowd with the rest of the population (Bauman 1991, 1998a, 1998b). Bauman views strangers as products of their position in modern or postmodern societies. Strangers produce uncertainty in those who belong because of their being *in* but not *of* a given society. Due to their ambivalent position, strangers become unwanted and are kept at a distance. This can be seen in relation to students with learning disability in terms of their physical and relational separation in special schools, or in special units and learning support classes in the mainstream school. In this way, students with ID are kept at a distance to mainstream education, despite inclusive rhetoric (Higgins et

al., 2006; Higgins et al., 2008; Kearney, 2009; Ministry of Education, 2010). This manifests itself in the way that students with learning disability are mostly strangers to mainstream school bureaucracies, systems services and professionals. In the post-school context, young people with learning disability can be said to be strangers to the wider community as a result of being placed in vocational service day centres and mostly participating through sanctioned activities with paid supporters. Bauman (1990a) has contended that the stranger enforces social and cultural boundaries and perpetuates the “us and them” dynamic. Strangers are “neither friends nor foe... [and] they cause confusion and anxiety” (Bauman, 1990a, p. 55). Strangers “reduce social, cultural and physical boundaries and ‘ambivalent people’ make them problematic” (Bauman, 1991, p. 55).

I argue that the deconstruction of community through neoliberalism has had a profound impact on the young people with learning disability in our study, and consequently on their opportunity to resist being cast as strangers. Bauman has explored the notion of the poor or underclass as not belonging to a community, but rather suffering as individuals not of a community, and suffering in silence. This situation can be translated to people with learning disability in that they are a group of individuals suffering mostly in silence, unable to meaningfully influence the community, to gain access or a voice in it, or to have a real sense of belonging to it. Self-advocacy groups for people with learning disability are vociferous, but in many ways only within their own community, and might therefore be seen as preaching to the converted. This is not a group who can easily seek solace within their own community – as, perhaps, with class, race, faith or ethnicity. As Bauman has said, to be poor is to be lonely.

“Flawed consumers”

More and more people are socially produced in the role of consumers while being denied access to the producer role. Such people are organically incapable to perform the consumer role adequately as well as deprived of the means which an adequate performance would require. (Bauman, 1983, p. 42)

Bauman (2004) viewed neoliberal capitalist societies as producing surplus populations that become the unintended casualties of economic progress (p. 39). It is debatable as to whether young people with learning disability should be understood as unintended or intended

casualties of economic progress. Either way, this identity acts to position them as the social other. In Bauman's work (1987, 1998a), the social other has been represented by the "flawed consumer." Bauman has contended that successful consumers are controlled by disciplinary power and become seduced by the free market into believing they are free. In contrast, flawed consumers want to be successful but because of their social and economic position are prevented from being a successful consuming self (Marotta, 2002, p. 43). The flawed consumers are the by-products of consumer society, necessary for it to be sustained and reproduced (Bauman, 1988, p. 187). These flawed consumers are sometimes categorised as the new poor, who are disempowered because they are bureaucratically controlled and managed (Bauman, 1988, p. 185). The relationship between self (successful consumer) and other (flawed consumer) is based on the other reaffirming the identity of the self. The flawed consumers thus become the strangers of the consumer society. Bauman (1997, p. 42) depicts them as "the 'inner demons' of consumer life that need to be repressed and metaphorically exorcised." The strangers or flawed consumers of the consumer era are required to reinforce the gap between self and other.

Cast as strangers to the active pursuit of consumerism in the hierarchically constructed material world, young people with learning disability are overwhelmingly welfare consumers and as such lack the currency to actively participate in open market consumption. They are mostly consumers of special education and welfare benefits without control of the funding. Personalised or individualised funding which might challenge this situation is only currently being trialled in New Zealand, as mentioned in Chapter 2. However, it will only change the situation if personalisation brings some measure of control over funding support, and if it is achieved in a reciprocal and respectful relationship with others. This reciprocal relationship must equalise the power dynamic ever present, an idea I take up in the final chapter.

"Collateral damage"

Bauman has used the military metaphor of "collateral damage" to describe when action is deemed appropriate despite having disastrous human consequences. These human consequences can be seen in a war zone, where the death of innocent civilians results from military action. In his book *Collateral Damage: Social Inequalities in a Global Age*, Bauman (2011) used the metaphor to describe the victims of social inequality. This is particularly

pertinent at a time in New Zealand where 20% of the population live in poverty and the gap between the rich and poor is increasing more rapidly than in any other OECD country (OECD, 2012). People with learning disability are overrepresented in the poverty statistics. Bauman (2011, p. 5) made the point that the collateral casualty's fate is most often decided by those who, like military generals, are not the ones directly at risk. It is most often those at the foot of the inequality ladder who suffer most from collateral damage (p. 8). This can be seen in the context of education and social welfare policymakers introducing policy that has intended or unintended consequences for young people with learning disability. The policymakers are overwhelmingly New Zealand Pakeha (white European), middle class people whose policy work incurs little risk to themselves but has potentially huge implications for young people with learning disability. As a professional working in the field of special and inclusive education, I am also heavily implicated in these exclusionary discourses.

Bauman describes natural disasters as another site where collateral damage plays out, and its casualties are again most commonly those who are poorest and disadvantaged. This can be seen in the collateral casualties from the devastating earthquakes suffered in Christchurch since 2010. For many people with disability, the earthquakes caused huge disruption and misery physically, emotionally, socially and geographically. Because many of vocational service buildings and resources were destroyed or severely damaged, many people were left traumatised, displaced and dispersed. The massive damage to the city's infrastructure caused great disruption and distress to those people who find it more challenging to "get out and about" relationally or geographically and are reliant on the restricted services and support available.

In acknowledging uncertainty and rejecting competitive individualism as a route to greater social equality and moral responsibility, Bauman has discussed statistics on the escalating gap between the rich and poor, the "haves" and "don't haves."

They challenge our all-too-common ethical apathy and moral indifference, but they also show, and beyond reasonable doubt, that the idea of the pursuit of a good life and happiness being a self-referential business for each individual to pursue and perform on his or her own is an idea that is grossly misconceived. (2011, p. 39)

I have sketched out the social thought of Bauman and his use of metaphors as a strategy for positioning young people with learning disability in contemporary New Zealand society. If they are to be included in the liquid modern pursuit of consumption, they require the resources and opportunity to do so; otherwise they risk marginalisation and exclusion. Furthermore, if they are to avoid being cast as flawed consumers, they require economic and social capital (Hughes, 2002, p. 580). Because meaningful, sustained, paid employment for people with learning disability is still highly unlikely in New Zealand, they are restricted from arguably one of the key pathways to escape being marginalised or excluded. Equally, away from the material realities of a liquid modern society, the cultural implications are just as challenging where physical, intellectual and aesthetic perfection are prized.

I argue that the students and young people with learning disability in this study are cast as strangers through what Bauman views as the universalising aspects of modernity that lead to exclusion. In this way, the stranger is continually constituted and then struck out (Hughes, 2002). Hughes (2002, p. 582) says that “Bauman’s hermeneutics embody the implication that modern culture is the process that transforms impairment into disability, bio-physical status into oppression.” In this way, liquid modernity continues to cast anyone “not normal” or “not ordinary” as requiring either assimilation or exclusion. What has relevance is whether the young people with learning disability have the desire and the opportunity to be productive and therefore seen as capable to engage in material and other valued forms of consumption.

I also understand that while young people with learning disability may not be viewed as particularly effective market consumers, this very fact may provide an opportunity for resisting being devalued or marginalised. Living non-consumerist lives is something valued and admired by some sections of the community, where the “simple pleasures” in life are acknowledged. Young people with learning disability might therefore take their meaning from something other than the market. From this perspective, an interest in what these young people perceive as important in the search for a good life has potentially reciprocal value for those without learning disability. What we can learn from the perspectives and lived experiences of young people with learning disability thus becomes valuable.

As described this research is not value neutral but actively seeks to challenge inequality that excludes people because they are different. Working within a DSE framework I am morally

compelled to challenge this situation. Having an ethical and political emphasis is important for transforming education and society. With an emancipatory intent and approach I can perhaps resist being seen as part of the problem (Allan, 2006; Barton, 1996). Freire's (1997) "call to arms" for hope as a challenge to accepting one's fate reminds us that to do nothing is to be complicit to inequality. Through daring to dream we can resist and reject towards new and exciting alternatives. New possibilities have the potential for transformative action (Allan, 2006; Freire, 1997, 1998). Through understanding, reflection and action I can acknowledge the complexities of the world and avoid "a narrow translation of research into practice" (Lather, 2013, p. 555).

This research is underpinned by an explicit ideology that views disability as a social construct, framed both structurally and ideologically through a network of unequal power relationships (Skrtic, 1991, 1995; Slee, 2001). The focus of the research described here is to understand what kind of life young people with learning disability want as they transition from school to post-school life. This will allow for a positioning of their lives and their journey within a disabling contemporary Western society. In order to achieve this I needed to understand the lived experience of young people with learning disability their life goals, aspirations and desires and what they consider a good life. Methodologically, in acting as an "ally," it required me to be collaborative in the decision-making prior to the research and importantly, to be responsive to it during the research process, but crucially to consider life after the study. Methodologically it compelled me to directly involve the subjects of the research in the process of research itself from its earliest stages.

It is crucial that as a practitioner researcher I am honest from the beginning about my own values because they will shape the research process from questions, methodology and design to dissemination and thereafter. However, as Barton (1996) says paving the way with good intentions provides no guarantee of success. I needed a reflexive, self-analytical, critical approach to issues of methodology. In undertaking this work I made a commitment to a collaborative, co-constructed research process in recognition that "understanding the appropriate relationships among self, subject, setting and research question will shape the quality of the final text in significant ways" (Navarro & Zeni 2004, p. 5). This thesis acknowledges that active, collaborative, reflexive and politically aware research must be receptive to the fluid, messy, ever-changing interpretations of lived experience. What is

critical is that these experiences are transparent and, themselves, become objects of study. Reflexivity was supported through the ongoing feedback I received from my lead supervisor. This enabled me to strengthen my thinking, be critical, and be aware of my own naivety and biases I brought to the research process. In this way reflecting on my research diary was another very useful tool to support greater reflexivity. This critical approach to research will challenge dominant cultural assumptions about the lived experience of young people with learning disability.

The focus and research questions of this study

Educational responses to inequality and exclusion that are founded on language and methods in education lacking a critical consideration of entrenched social, political and cultural mechanisms will not transform the material conditions that underpin exclusion in society (Connor, 2008; Freire, 1998). My interest in this research is how young people with learning disability can successfully transition from school in their search for a good life. I am interested in making sense of and promoting the lived experiences of young people with learning disability in education and society as a vehicle for their emancipation. Insights gained have the potential to support greater equity, opportunity, contribution and belonging in education and society for young people with learning disability in our collective journey towards a good life.

Main research question

- Young people with learning disability and their understandings of a good life?

Sub-questions

- What are experiences of young people with learning disability during the transition years?
- What does exclusion mean for young people with learning disability?
- What are the effects of an exclusionary landscape in school and society?

- How can the views and perspectives of young people with learning disability inform inclusive and special education policy and practice?

CHAPTER 4: METHODOLOGY

In Chapter 3, I presented a discussion on a range of theoretical perspectives and understandings that I drew from as “tools for thinking” to inform the methodology for this study (Slee, 1997). In writing this thesis I recognise the crucial importance that methodology has played in the telling of this research story and its outcomes. There is a requirement for rigour and transparency when dealing with the methodological issues and tensions inherent within qualitative research (Cohen, Manion & Morrison, 2007).

Our study demonstrates a reflexive approach in chronicling the co-researchers and participants within the research as an important part of the methodological insight and the decisions made on the design and methods used. Kirsch (1999) stated:

Reflective accounts of research are important because they remind readers that scholars are always products of their culture and history, that observations are always limited and partial, that interpretations are complex and contradictory, and that all accounts of research are open to revision and reinterpretation. (p. 82)

As such, the subjects of research and the researchers themselves are never outside the power of institutions and social processes, just as the subjects of research can never be totally free of the influence of the researcher and their paradigmatic choices. This research attempted to blur the line between the subjects and the researchers in realising a situation of subjects becoming researchers and researchers becoming subjects.

Definition of methodology

Schwandt (1997) presented a definition of methodology as the

theory of how inquiry should proceed. It involves analysis of the principles and procedures in a particular field of inquiry that in turn govern the use of particular methods. The study of methodology includes topics in social science (e.g. explanation, theory, causality and so on) and philosophical anthropology (the study of human nature). (p. 93)

Meanwhile, Bogdan and Taylor (1975) defined methodology in general terms as referring to

the process, principles and procedures by which we approach problems and seek answers. In social sciences the term applies to how one conducts research. As in everything we do, our assumptions, interests and goals greatly influence which methodological procedures we choose. (p. 3)

These are broad definitions of methodology and so tend to separate methodology from values. Conventional social research relies too often on techniques that epistemologically separate the researcher and the research subject. These techniques imply that the researcher has superior status in relation to “research knowledge” and an ability to interpret what is going on at a deeper or more sophisticated level than the “local stakeholder.” The researcher is also seen to own the data, because it only becomes meaningful when handled by the research professionals.

Importantly, our study moved away from this conventional view of research methodology in providing a space for alternative voices and exploring ways of constructing and co-constructing alternative and shared realities. By promoting a research agenda that allowed space and time for conceiving individual and shared identities, we created opportunities for ontological reflection. This allowed for new identities to be crafted and celebrated.

Meaningfully including students with learning disability in research as co-researchers and participants presented many challenges, and I accepted that this meant adaptations to the design and methodology that might defy scientific “rigour.” I believe this was well balanced by increased social validity and real world relevance (Nind, 2012). I considered myself an “ally” in the context of this research, and the process as a “joint enterprise,” as there was a shared goal with the research aim to improve post-school outcomes for young people with learning disability. I recognised my limitations in terms of my lack of lived experience, and therefore considered it an absolute requirement to involve young people with learning disability in leadership roles from the earliest stages, ethically, morally and methodologically. A key aim would become an exploration of what ‘doing’ inclusive research and being an inclusive researcher means.

The methodology was inclusive and founded on the co-construction of knowledge that would lead to shared understanding. In providing an “active voice” for young people with learning disability through the research process, new understandings about the lived experiences, goals and aspirations could be provided. In addition, the opportunity for both people with and

without learning disability to see Andrew and Caroline as co-researchers and co-conductors of the research process said much about how their knowledge was privileged.

My methodological position

Carlson (2010) asked an important question when she wondered “who is the expert?” in relation to learning disability research. Knox, Mok and Parmenter (2000), for instance, described “working with the expert.” By assuming the role of “expert,” what does this assume about the role played by the expert? What authority does someone have to assume the role of expert and what responsibilities does it bring? Is there a measure of autonomy when assuming moral authority? I align with Carlson in moving beyond an individualistic model of autonomy. This allowed a move away from a viewpoint where moral authority resides within an autonomous individual to one where it is situated within relationships. Carlson also discussed epistemic authority and the dangers of assuming knowledge about the kind of life people with learning disability want. I cannot and never will be able to assume epistemic authority with regard to knowledge claims concerning people with learning disability. However, I can, as Kittay (2010) has articulated, ensure that I assume “epistemic responsibility and modesty” in my relationship with Andrew, Caroline and the focus group participants. In our study, I considered us all as experts who were capable of contributing positively to the research process.

Through this research, I was able to explore my personal and professional position and motivations for involvement in this research project. What were my “true” motivations for conducting this form of research? Was it valid to have personal motivations within the field of DSE and inclusive research, and how did this influence the methodology? What were the methodological parameters for this form of research? In answering these questions, I recognised my unique position as a practitioner (teacher) researcher – as described in Chapter 1 – and my belief in the Teacher Leadership movement and its distributive, collaborative, action-orientated forms of practice (Frost & Durrant, 2002; Frost, 2007; Gladstone, 2009). I held and continue to hold a firm belief that this form of educational research is at the heart of effective teacher-led, school based, best evidence research (Alton-Lee, 2003) and can directly inform the school development process (Hargreaves, 1996; Frost, 2007). In the United Kingdom context, Hargreaves (1996) has described the dilemma of educational research and

the importance of practitioner-based research in schools by teachers identifying and researching a concern in their everyday practice:

Educational researchers write mainly for one another in their countless academic journals, which are not to be found in a school staffroom. It is this gap between researchers and practitioners which betrays the fatal flaw in educational research. The flaw being it is the researchers and not the practitioners, who end up determining the agenda of educational research. If practicing doctors, especially those in hospitals, stopped doing research and left it almost entirely to a special breed of people called “medical researchers“ who were mainly university academics without patients, then medical research would go the same way as educational research a private, esoteric activity, seen as irrelevant by most practitioners. (Hargreaves, 1996)

In support of Hargreaves’s view, it is important to state my belief in the unique position practitioner researchers have within research in that they, and therefore I, are privileged to be already working closely with students on a day-to-day basis, as I was with those who became key participants in our study. This was significant because it provided a “unique intimacy” and in this case a “shared goal” for us, as perhaps distinct from some academic researchers who may be more constrained by institutional expectations and funding issues. These academic researchers are influenced by agendas that may constrain them and lead to outcomes that arguably have little impact on the subjects of the research.

My daily teaching practice within schools allowed a relationship with the students that provided insight to their lives. Although the privileged relationship with the students I work with may not be described as “insider” knowledge, it certainly meant I had a “foot in the door.” My role as co-researcher created more opportunities for reflexivity than if I was detached or an “outsider.” While there were potential dangers to the research in my being this close to the participants, there were also opportunities for developing theory and communicating findings that may have been missed by an outside, naive inquirer (Ellis, 2004). Thus, I deliberately took the decision that my personal and professional life would become part of the process. Indeed, I believe it provided richer, deeper insights.

Reinharz (1997, p. 3) described the qualitative researcher as “the key fieldwork tool” and suggested that researchers bring, and create multiple selves in the field that are constructed through relationships and lived experience. This emotional connection had relevance in our

study. Harrison, MacGibbon and Morton (2001) described researchers' personal and emotional experiences in the field as potential sources of "transgressive" data. My emotional involvement with the young people as a teacher, co-researcher and friend provided opportunities for this added interpretation of our experiences. In recognising "transgressive" or emotional data (St. Pierre, 1997), I have been able to enrich my understanding of the research process and think about different kinds of data that might produce different knowledge in participatory research. This has allowed me to add to the often linear nature of the narrative of knowledge production in research methodology, where we first employ methods – like focus groups – that produce data and then code, categorise, analyse and interpret those data to develop theories of knowledge. In Chapter 7, I have drawn on this emotional relational data for the deeper understanding it provides.

Epistemological and ontological considerations

Before any research project can take place, a number of decisions need to be taken regarding its purpose, the desired outcomes and the appropriate methods for securing these aims. Hitchcock and Hughes (1995) made the point that methodological considerations arise from ontological and epistemological assumptions about the nature of reality and knowledge. The two paradigms in ontological and epistemological terms are generally named "positivist" and "interpretivist." The positivist seeks the facts or causes of social phenomena, with little regard for the subjective states of individuals. The interpretivist is concerned with understanding human behaviour from the actors' own frames of reference and examining how the world is experienced (Bogdan & Taylor, 1975, p. 2).

The positivist tradition has been dominant in social sciences, taking its lead from the natural sciences in adhering to the idea that the world is an objective reality that can be measured and is subject to causal laws (Cohen, Manion, & Morrison, 2007). The purpose of social science research, according to the positivist viewpoint, is to establish objective knowledge that can be used to understand and predict human behaviour. The interpretivist approach, by contrast, proceeds from ontological assumptions that the world exists as a product of the individual consciousness and that reality exists through the experiences of the individual, such that knowledge is not value-free but subjective (Anderson, Mason & Shirey, 1986). Kershner and Chaplain (2001) outlined one important contrast between "positivist" approaches, which

attempt to discover general laws governing aspects of human thinking and behaviour, and “interpretative” approaches, which attempt to understand the relationship between people’s idiosyncratic experiences, beliefs, feelings and actions in everyday social situations. Between these two extremes lie various shades of grey, but the debate surrounding the two paradigms is important with regard to the nature, purpose and possibilities of social science research.

The dominance of the positivist paradigm has been challenged by exponents of interpretivist research with increasing fervour over the last thirty years. The questioning of what scientifically rigorous research is, and what its effects are, is part of a contemporary condition that Habermas (1975) has called a “crisis of legitimation” and which others have called “postmodernity” or “postpositivism.” The key issue is the ability of educational or any other social science research to produce causal laws in the same way as natural science research. The establishment of causal laws governing the social world might be attractive to policymakers but is, in my view, both philosophically alarming and practically inadequate. On a philosophical level, it implies a reductionist view which precludes human agency and free will.

Interpretivism

This research draws on interpretivism, which is underpinned by a social constructionist epistemology (Burr, 2003; Crotty, 1998). An interpretivist perspective is interested in social life as it is constructed and experienced by individuals within their lived contexts (Ferguson & Ferguson, 1995). Researchers working within an interpretivist paradigm use ethnographic, descriptive and narrative details of people in their day-to-day contexts as the basis of their data collection, interpretation and analysis (Ferguson & Ferguson, 1995). Ferguson and Ferguson (1995, p. 107) suggest that giving members of marginalised social groups a voice by promoting opportunities for them to tell and have their stories heard can have a transformative impact on social relations at the macro or policy level, stating that “in its emphasis on complete description of individual cases, interpretivism eventually challenges inequity by legitimating the perspectives of those on the bottom of society.” They further suggest that interpretivism is a useful approach to researching disability because of the particular questions that it raises. For example:

What is the experience of disability? ... That is, ask for the context, the social construction through which social reality takes shape. Interpretivism maintains that disability is not a fact – an entity- whose nature is waiting to be discovered. Disability is rather an experience waiting to be described or, more precisely, a multitude of experiences waiting to be described. (Ferguson & Ferguson, 1995, p. 113)

The experiences of young people with learning disability as co-researchers and active participants in this study over an extended period of time presented opportunities for understanding disability from the “inside” (Ballard, 2003). Gabel (2005, p. 17) considers that research in disability studies is “primarily concerned with the view of issues and problems as defined by people with disability and as they relate to social exclusion and oppression.” In giving young people with learning disability an opportunity to research the views and perspectives of young people with learning disability, our study offered opportunities for interpretations that went beyond the “typical” researcher/researched relationship. In this way, it can be said to have made a contribution to the emancipatory project.

Social constructionist and interpretivist thinkers view knowledge as the outcome of relational, cultural and subjective meaning-making processes (Ferguson & Ferguson, 1995; Slee, 1997). Knowledge is the temporary outcome of interpretation, negotiation and co-construction. The articulation of particular meanings, through human action and society, are assumed to have differential outcomes for particular individuals and groups. Interpreting and understanding social action through recognising the making of meaning in the relationship between individuals and our social, political and cultural contexts are ideas explored throughout this thesis. From interpretivist, socio-cultural and emancipatory perspectives, the thesis promotes lived experience as essential to constructing and making sense of human reality and action (Ballard, 1994, 2003; Freire, 1997, 1998).

Organising the research methodology

To organise a methodology for our study founded on knowledge and understanding that is relational, I formulated the schema in Figure 2 to explain how we conducted the study.

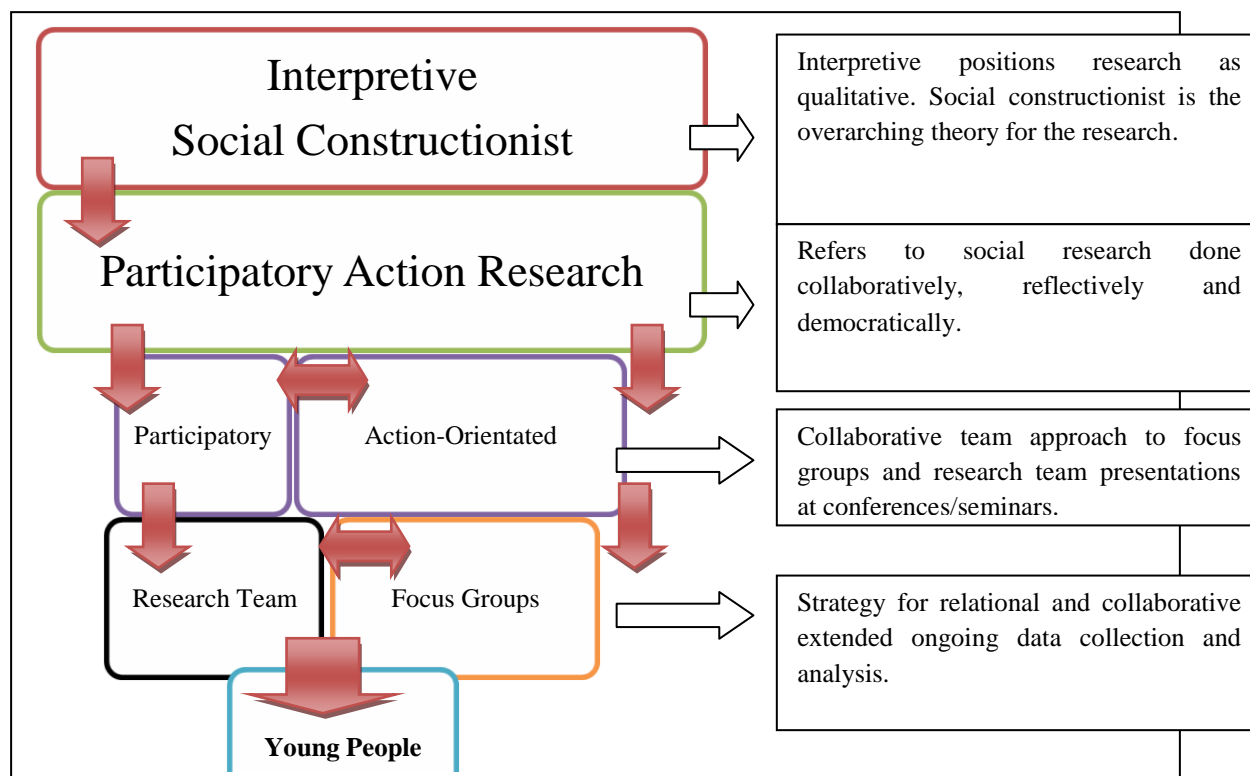


Figure 2: Unpacking the research methodology

Approaches to disability research

Debates have arisen within disability studies and DSE concerning whether the nature, form and content of disability research has been exploitative, objectifying or oppressive. The broad critique is encapsulated in Thomas's observation:

In the way it has been conceived, organised and conducted, as well as in the nature and use of results, representatives of professional groups have carried out traditional disability research in medicine, rehabilitation, psychology, sociology and social policy with little or no consultation with, or involvement of disabled people themselves, other than as research subjects. (1999, p. 152)

Thomas argues that traditional forms of disability research have been implicated in mediating and intensifying people with disability and their oppression. With this perspective has come a rejection of the assumptions of the traditional individualistic approach to disability research, making way for what has come to be known as emancipatory research – albeit in a range of guises. What has variously been termed “critical inquiry,” “praxis” or “emancipatory

research” (Oliver, 1992, p. 110) has been developed into a new framework for disability research. This emancipatory paradigm emphasises the political project inherent in the research endeavour, foregrounding the role of research in promoting the interests of oppressed groups (Barnes, Mercer & Shakespeare, 1999, p. 215). Distinct from participatory research, in which people with disability are simply involved in the research process, an emancipatory practice argues that research should be controlled by people with disability as part of a broader process of empowerment (Zarb, 1992, p. 51). Integral to this re-envisioning of disability research are changes to the material and social relations of research production, including a reassessment of the role of funding bodies and the relationship between researchers and those being researched (Oliver, 1992; Zarb, 1992). Some disability researchers, however, have questioned whether research can ever be emancipatory on its own, without other forms of action (Shakespeare, 1997; Broun & Heshusius, 2004).

Traditional forms of learning disability research

Until recently, a significant amount of research has had a largely disabling effect on people with learning disability through its emphasis on curing, modifying, describing and classifying impairments or inabilities (Rioux & Bach, 1994, Goodley, 2000). My examination of the literature on more traditional forms of research practice and anecdotal evidence from informal conversations with young people with learning disability, their parents and supporters leads me to believe that many non-disabled policymakers and professionals still institutionally and attitudinally oppose the emancipation of people with disability. There is still a manipulation of the research process, the researcher and the researched in order to further oppressive personal and political interests.

Rather than trying to understand the lived experience, traditional forms of learning disability research have sought to reduce or prevent it. Ongoing medical programmes like amniocentesis that encourage parents to abort foetuses showing signs of disability are but one example of this medicalisation and eugenic desire to eliminate intellectual impairment. The medical sterilisation of people with learning disability is still a contentious issue today, and I have personally been involved in discussions with parents wishing to prevent their daughter ever becoming a mother. In addition, people with Down syndrome, as with co-researchers Andrew and Caroline, have been the subject of questionable medical practices such as facial

reconstruction and tongue surgery. This practice was concerned primarily with making the person more socially acceptable (Lynch, 1990).

For people with learning disability, there has been an ongoing desire by the medical and psychological bodies to classify, standardise and quantify individuals in terms of mental functioning or IQ. However, the World Health Organisation's Classification of Functioning, Disability and Health (ICF 2001) has acknowledged the disabling impacts of society on the individual's experience of impairment by "conceptualising an interaction between intrinsic features of the individual and that person's social and physical environment" (Bickenbach et al., 1999, p. 1183). This is seen as an attempt to separate that which is properly in the domain of medical practice from that which is in the domain of social and environmental factors. Although this recognition is positive, the World Health Organisation's ICF has still been accused of using a closely guarded definition of how people across the world think, feel and act. It can thus be still accused of objectifying people with learning disability within a bio-medical discourse.

The impact of psychological testing, such as IQ testing, is another example of how people with learning disability have been monitored, labelled and assessed through the development of psycho-educational practices and regimes. This has had a major impact on this group of people over recent decades, as individual scores on these scientific classifications have been used to label those tested in order to decide whether and to what level they are considered educable. Historically, this meant differing education pathways for those deemed "slow" – typically the vocational training route at best, or access to a curriculum of "stagnation" at worst (Nash, 2001) – contributing the high prevalence of these young people leaving school with no qualification. This science has been used by health, social and education services to allocate resourcing and in the general management of people with learning disability within a restrictive environment (Rose, 1998; Nash, 2001).

The field of rehabilitation within the arena of social, psychological and educational research has meant an abundance of "therapy" and "treatment" for people with learning disability. This has focused on helping people to overcome, adapt or cope with their impairment (Rioux & Bach, 1994, p. 2). Simultaneously, as described in Chapter 1, special education practices have been developed that have and still do exert power and dominance over the everyday

lives of young people with learning disability and their families. This group of professionals and researchers have created an industry, with all its inherent service systems and ideologies, the purpose of which is to maintain professional control and adjudicate over the problems that are still defined within the individual (Dempsey & Nankervis, 2005). They and their service systems are the gatekeepers to resources and regulate access to nearly every aspect of people with learning disability and their lives, including education, housing, employment, healthcare, leisure and relationships.

In these respects, bio-medical, positivist and psycho-reductionist forms of research have objectified and silenced the voices of people with learning disability and have often dehumanised them in the eyes of society. Research that has tested and classified people with learning disability in an attempt to predict educability has acted to exclude. These forms of research, almost entirely by researchers without disability, have dominated the research landscape and constructed the individual with learning disability as the problem “other.” This focus by social research has blurred the intersections of structural discrimination and marginalisation for people with learning disability, with the result that these people have viewed this form of research with scepticism (Mitchell, 1999).

As discussed in Chapter 2, human service philosophies, policies and practices including normalisation, SRV and QoL have focused more on the “voice” of people with learning disability and have in many instances mandated their participation. These approaches have had their limitations, including a foundation in patriarchal, under-developed theoretical frameworks and inadequate methods. However, they have made it possible for people with learning disability to begin to “be heard” under certain conditions. New forms of participation have been incorporated into service and research philosophies, although there remains little evidence in my experience that this has translated into meaningful practical change in school or service delivery.

Research within a DSE framework

A DSE approach to methodology has influenced this study. I have read much critical and emancipatory writing by DSE members, presented at DSE conferences overseas, and was on the committee that brought the DSE conference to New Zealand for the first time in 2013.

This has allowed me to become part of a community of researchers from different disciplines who come together in promoting and privileging the knowledge and expertise of people with disability (Connor, et al., 2008). Through this exposure to multiple views and perspectives on people with disability, I have become aware of the diversity and differences that exist among people with disability (Goodley, 2001). Importantly, my experience with DSE has also allowed me to promote and privilege the knowledge and insight of young people with learning disability as a minor but growing voice among this particular community of researchers.

DSE has encouraged me to challenge the expert-based systems of knowledge that govern the response to disability and difference (Bogdan & Taylor, 1992; Slee, 2001a; Ware, 2006). Roger Slee (1997) describes DSE as “a project in cultural politics.” Gabel (2005, p. 9) suggests that DSE

research is concerned with a Freirian form of praxis, or a conscious effort at social change that brings about equity, social justice, and full participation in society where the work toward social change is led by those who are themselves, oppressed.

I interpret this as implying that it is my ethical and moral responsibility to actively support the unique insights and aspirations of students and young people with learning disability with a view to supporting educational and social transformation. It is this call to arms that resonates with the intentions described in this thesis. No longer should young people with learning disability be railroaded from early on in their secondary school life – and earlier – along a restrictive pathway that they do not want and that continues to reinforce their exclusion from the communities in which they live. I seek to expose, challenge and reject traditional special education “expert” understandings (Slee, 1997; Ferri, 2006).

The next section details the major methodological issues within learning disability research that defined my decision-making on the research design.

Emancipatory forms of learning disability research

Translating theory into the practice of emancipatory research has become somewhat contentious in relation to research and people with learning disability (Walmsley 2004).

Designing, conducting, reporting and evaluating the outcomes and the ending of research according to an emancipatory paradigm is complex. It may involve considerations that have not been fully anticipated by those who promote the paradigm within disability studies and DSE. Factors such as the form of the participant/researcher relationship, personal commitment, time and the requirement for that time to be invested over long periods with no clear limits from the beginning provide considerable challenges to the emancipatory project. The intersection of the personal and the professional in learning disability research is an important idea taken up in this thesis.

The collaborative, reciprocal act of identifying a concern in the lives of people with learning disability that needs changing, questioning the conditions that create or sustain that concern and talking about a solution can form the basis for the development of an emancipatory consciousness. Through this process, young people with learning disability can develop awareness that research can tackle concerns that are relevant to their lives. In doing so, the emancipatory research process addresses complex material, historical, social, political and cultural relations and can find solutions to young people with learning disability's search for a good life.

As Nind and Vinha (2012) suggest, the involvement of people with learning disability in "doing research" is not new. However, the true nature of how, why and in what way is not always clearly articulated in the literature. The debate about the context, process and impact of disability research has both facilitated and required new approaches to research involving people with learning disability. As a result, it has created a new level of epistemological and methodological complexity and curiosity for researchers in the field. Such frameworks promote research that is grounded in and guided by the views and interests of people with learning disability themselves, while at the same time acknowledging the criteria of academic institutions or funding bodies for scholarly rigor and accountability. In recent years, research partnerships between self advocacy groups and academic researchers have been the most frequent result. However, our study was not rigidly governed by adherence to funding body requirements. Instead, it evolved from the shared, practical concern of Andrew, Caroline and I about what happened to young people with learning disability after they left school.

Researchers without disability now conduct research that recognises people with learning disability as reliable informants who hold valid opinions and have a right to express them. There is more recognition that individuals with learning disability are the best authorities on their own lives, experiences, feelings and views (Stalker 1998, p. 5). New approaches look for meaning and knowledge in the lived experience of learning disability and involve elements of anti-positivist, postmodern, qualitative, reflexive, feminist and post-structural research. In the field of learning disability research, these approaches are seen in types of methodologies including narrative (Booth, 1996); participatory (Kiernan, 1999; McClimens, 1999); performative (Boal, 1995); discursive (Corker & French, 1999); ethnographic (Goodley, 2000); and collaborative (Williams, 1999). Our research drew from a range of these methodologies in arriving at a suitable design. Importantly, people with learning disability themselves have begun to undertake their own research and write about their experiences (see, for instance, Aspis, 1999; Hughes, 2002; March, Steingold, Justice, & Mitchell, 1997; Palmer & Turner, 1998; White with Morgan, 2012). These groups and individuals have challenged what actually constitutes research (Williams, 1999, p. 48).

Within learning disability research, the terms “emancipatory” and “participatory” have often been used interchangeably. This has led to confusing and similar references in the literature (Northway, 2000; Stalker, 1998; Walmsley, 2001). Kiernan (1999) suggests that difference is one of emphasis, but Oliver (1997) refers to a fundamental distinction. Oliver sees participatory research as leaving the social and material relations of research “untheorised and untouched” (1997, p. 24). Northway (2010) identifies the difference as one of participation and control.

Perhaps as a consequence of this debate over the past decade, approaches to research with people with learning disability have begun to appear under the umbrella of inclusive research (Walmsley, 2001, 2004; Walmsley & Johnson, 2003). However, the term “inclusive” has its own problems. Inclusive research describes research in which people with learning disability are involved as more than just passive research subjects or respondents. Walmsley and Johnson (2003) describe inclusive research as

a range of research approaches that traditionally have been termed “participatory,” “action” or “emancipatory” (Freire 1970; Reason 1998). Such research involves people who may otherwise be seen as subjects for the research

as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users. (p. 10)

Bigsby and Crawley (2010) raised an important issue when they pointed out that “seldom ... does research that claims to be inclusive give detailed descriptions of the involvement of people with an intellectual disability, their roles, contribution, the challenges encountered, or the support provided” (p. 54). Grant and Ramcharan (2009) found that it still remains more common for people with learning disability to be involved in smaller roles – serving on advisory committees, assisting with recruitment, collecting data, advocating or supporting peers and disseminating findings – rather than in the whole process. Walmsley (2001) has said that “most people with learning difficulties need allies to do research” (p. 198). She stated that

whilst disabled people can and do conduct their debates without reference to members of oppressive groups, people with learning difficulties still rely on a team approach, and few have been able to argue that without this team approach, people with learning difficulties would be in a position to research and publish. (p. 200)

Walmsley also raised important issues concerning the link between accessibility, on the one hand, and theorising, on the other, as areas for fruitful debate within learning disability research. She contended that the requirement to make research accessible problematises the opportunity to theorise. The dilemma that Walmsley described between accessibility and theorising was tackled and somewhat mitigated in our study through the collaborative approach and design the research team adopted.

Johnson (2009, p. 252) provided a number of points that guided our study. I summarise them below:

- The research question, problem or issue must be one that is owned (though not necessarily initiated) by people with learning disability.
- It should further the interests of people with learning disability.
- It should be collaborative.

- People with learning disability should exert some control over the process and outcomes.
- The research question, process and reports must be accessible.

Our inquiry was driven not only by concern about the post-school lives of young people with learning disability but also by the hope of what might be and the possibilities for defining how we as unique individuals can collectively make the journey towards a good life.

Goodley (2004), in an editorial for the *British Journal of Learning Disabilities*, raised important consideration for the methodological journey that informed our study:

A key concern in relation to disability studies is the nature of research production; in particular, how research can be developed in truly participatory ways to meaningfully include people with learning difficulties as co-researchers. (p. 50)

Methodologically, I have positioned learning disability as a socially constructed phenomenon, drawing on the interpretivist theoretical framework that provided the foundation for the collaborative methods adopted. The relational dimension that is described in Chapter 7 and further discussed in Chapter 8 presents young people with learning disability as capable, insightful, purposeful and resilient, with high expectations for their future lives. Importantly, this social construction views all people as interdependent to a greater or lesser extent and paves the way for an emancipatory intent.

I have drawn from a number of emancipatory studies for the theoretical and methodological insights that informed our participatory research process (Chapman & McNulty, 2004; Dowse, 2009; Garbutt, Tattersall, Dunn, & Boycott-Garnett, 2009; Kellett 2005; Knox et al., 2000; Nind, 2011; Nind & Vinha, 2012, 2013; Walmsley 2004). However, detailed accounts of the specific research procedures and methods used by researchers and people with learning disability to access, analyse and interpret research data have not been well-documented in the literature (Tuffrey-Wijne & Butler, 2009). Our study sought to add knowledge to this gap in the research, and this effort is described in the following sections.

A participatory action research methodology

In describing our study as having utilised a participatory action research (PAR) methodology, I draw on the contested and complex nature of conducting research with people with learning disability. I now consider what the recent literature has said concerning PAR and people with learning disability. As I claimed in previous sections, the literature includes differing interpretations of what exactly constitutes emancipatory, participatory or inclusive research, but I assert that our study was emancipatory in its intent and in its action. First and foremost, I consider our study to have been a democratic activity (Grundy, 1987, p. 142). It was also collaborative and action-orientated with respect to the team approach we adopted, in the way we collected and analysed data, and in terms of how we reported and disseminated findings. As such, the study demonstrated the critical stance that a DSE perspective takes in actively seeking empowerment and transformation as a goal for disability research in education. In this way it was also very much inclusive research.

The issue of research leading to action is not new. For instance, Becker (1967) advocated that “action-oriented” research was the way forward if research was to make a difference. The origins of PAR can be seen in the work of Freire (1970), in which the oppressed are transformed through a new awareness of self into active agents in the transformation of their life and the life of others. This certainly reflected the emancipatory endeavour in our study. The use of dialogue as a critical way of examining what we know and how to create new meaning provided a “tool for thinking” in our research design and the focus groups we utilised. This followed a Freirian understanding of dialogue as liberating through the process of listening, reflecting and transforming (Freire, 1970). In this way, dialogue becomes meaningful in communicating the different capabilities and experiences of the co-researchers and participants in our study.

According to Reason and Bradbury (2001), participation is the defining characteristic of action research. The centrality of participation in action research is based on a view of the world that consists “not of things but of relationships which we co-author” (Reason & Bradbury, 2001, p. 9). Action research involves a particular kind of interdependent relationship that blurs boundaries between traditional roles of researchers as “expert” and the

researched as “participants.” We all become “experts,” but with different expertises to contribute.

In relation to their research on quality of life indicators, Schalock, Bonham and Marchand (2000) supported the increased use of PAR. Jurkowski (2008) highlighted some important characteristics of a PAR approach with participants with learning disability that informed our study: (a) participants and researchers are actively engaged in the research process; (b) there is co-learning; (c) participants are empowered through the research process; (d) participants’ capacity to participate in decisions that influence their lives increases; and (e) there is a balance between the research being conducted and action taken to address the problems being examined. In their New Zealand study, Conder, Milner and Mirfin-Veitch (2011) concluded that PAR was a suitable methodology for engaging with people with learning disability.

Indeed, there has been a good deal of interest recently in PAR as a particular methodology for people with learning disability (see, for instance, Bigby & Frawley, 2010; Conder et al., 2011; Grant & Ramcharan, 2007, 2009; McClimens, 2008). This research directly informed our study design. In their research about a quality of life tool, Conder et al. (2011) drew on the recent work of Bigsby and Frawley:

Bigby and Frawley (2010) identify the difficulty they had engaging their co-researcher in reflecting, analysing, and writing about the research, but acknowledge that when these issues are situated within the lack of ownership he may have felt towards the study, and the expectations that they had of him, such an outcome may not be surprising. (p. 39)

The co-researcher team approach adopted in our research partly overcame the issue of ownership highlighted in the study by Bigsby and Frawley (2010). The research team approach deliberately sought early on to create ownership through our shared concern for the post-school outcomes of young people with learning disability, albeit from different perspectives. What is important is that the coming together of different people with different perspectives allowed for the generation of dialogue that can transform and find solutions to concerns. The acknowledgement in Bigsby & Frawley’s research that the co-researcher did not like the more technical or analytical aspects of the data analysis raises an important point as to how we designed our study, which was founded on the co-researchers and participants being viewed as capable and competent. One of our first tasks was to discuss our strengths.

We found that Andrew was not particularly keen on the perhaps more mundane analytical activities of our research, whereas Caroline would quite happily spend a couple of hours reading through data transcripts looking for meaning in themes. Caroline also took on other office tasks, such as team meeting minutes. In considering what we were each good at and perhaps not so good at, our research recognised the importance of individual roles based on our interests and capabilities where possible (Conder et al., 2011). This was an important realisation for me.

Perry and Felce (2004) provided some evidence demonstrating that people with learning disability can be supported to be competent data collectors and to hold positions of responsibility in the research process. They used the term “co-worker” and tested to see whether interviewer characteristics affected interviewee response, as found in studies by Dailey and Rene (2001) and Cleary, Mechanic and Weiss (1981). As a result of Perry and Felce’s research, I ensured that an initial 6 week period of training was put in place. Andrew and Caroline proved to be effective data collectors, reinforcing Perry and Felce’s findings.

Williams et al. (2005), in their research project with the United Kingdom self-advocacy group People First, called for the consideration of power relationships in the ways PAR tasks are allocated. They questioned whether people with learning disability can be meaningfully involved in data analysis and pointed out the need for “honest accounts of practice [to] help us all consider the issues and dilemmas, and thereby contribute to theory” (Williams et al., 2005, p. 33). However, our study provided evidence to suggest that Andrew and Caroline were capable of data analysis.

In his PAR research studies, Kitchin (2001) found that an important factor in the success of a research project with people with learning disability as co-researchers was how familiar with one another the researchers with and without disability were. The findings from our study indicated this to be a significant factor for success. Andrew, Caroline and I had known each other for over five years in the roles of student and teacher, and during the research we became co-researchers and friends. The evolving nature of our relationship was a positive feature.

My examination of pertinent PAR literature informed how I proceeded with the collaborative design. According to McClimens (2010),

it should be possible to exist as a person with learning disability *and* as a member of a research team, and to toggle between the modes seamlessly. If this was proving too difficult to do then the design needed to be altered to fit. (p. 64)

The above quote gives a good illustration of the importance of research design in this participatory study and explains why I will give particular attention to describing the methods used. The methods used in this study promoted a shared and democratic approach to transformation (Armstrong & Moore, 2004). My examination of the literature has found very few studies that describe the methods used from PAR with young people with learning disability. Research that describes the process from the origins of a study through to life after it has been completed is rare, as concluded by Kramer, Kramer, Garcí'a-Iriarte and Hammel (2010).

The next sections will explain the research design, including the origins of the study, the research team, consultation, recruitment, ethical approval and issues, data collection and analysis, limitations, findings and dissemination. The flexible approach adopted reflected the overall aims of the research and was, as with all research, a matter of “best fit” and compromise (Lewis and Lindsay, 2000).

Research design

This qualitative research was informed by its iterative process, which suits the participatory action orientated methodology. It allowed for interplay between elements of the research, for instance when data collection and preliminary analysis were supplemented with further collection and ongoing analysis. Themes emerged, changed and re-emerged through this iterative research process, particularly through the research team journey, conference presentations and writing-up phase. Andrew, Caroline and I brought individually constructed understandings of the research to team meetings. Collaborative understandings from individually constructed meanings were created through talk, shifting each individual team member's understandings in the process. Collaborative dialogue led to the revision and refinement of analyses and documents (Paulus, Woodside, & Zeigler, 2008).

The origins of this study

This study was developed from conversations with young people, their parents or caregivers, families, teachers and people involved in the transition process over a two year period from early 2008 to the end of 2009. I had returned to New Zealand from the United Kingdom at the beginning of 2007 and taken a teaching role in what was called the “transition class.” The conversations were both formal and informal discussions with young people and parents or caregivers, as I listened to the narratives of fear for the future and dissatisfaction for those who had left with how the young people’s lives had unfolded. One parent described this fear of the unknown as “like falling off a cliff.” What struck me most was listening during class time to the students describing stories about their dreams and aspirations for the future. Andrew and Caroline were students in my class and they expressed their anxieties for themselves but also for their friends.

The transition planning and meeting process provided the main vehicle for formal discussions. Many teachers felt they didn’t have the right knowledge, tools and viable pathways to offer in supporting the young people to their next stage in life. To provide a vehicle for this professional dialogue, I set up a teacher’s transition support group in mid 2007 where we could share ideas and practice.

The study was also developed as a natural progression from the Wayne Francis Charitable Trust project that I had been involved in as a co-facilitator (Cleland, Gladstone & Todd, 2008). This project, coupled with a deep sense of personal concern about how I could influence positively the lives of these students as they made the transition from school, provided the impetus to enrol part-time for my PhD in 2008. I told Andrew and Caroline about enrolling and they were interested, particularly in what it would be like to be at university, but also what I would study. They immediately wanted to support me, and from that day the idea of how I would go about conducting the research was borne. Andrew and Caroline would be involved – but how and in what way? It was decided to “do the research” together, and so the journey started.

Our research presented opportunities for exploring and understanding the intersection between “self” and “other,” particularly regarding the complex interplay among and between co-researchers and participants and their influences on the research process and findings

(Fine & Weis, 2002). Table 1 illustrates the “action as praxis” phased approach to this research.


Phase 1: Design and Procedure	<div> Ongoing data collection and analysis Ongoing research team meetings </div> 	
<ul style="list-style-type: none"> • Establish the research team – rules of engagement • Ethical approval • Period of training – discuss, identify, clarify research problem/questions • Clarify research design, procedure, methods • Sampling strategy and obtain consent 		
Phase 2: Data Collection and Ongoing Analysis		
<ul style="list-style-type: none"> • Design protocols for focus groups • 3 focus groups over 15 months – school students + questionnaire • 2 focus groups over 1 year – young adults left school in the last 5 years • Follow-up interviews 		
Phase 3: Findings, Reporting and Dissemination		
<ul style="list-style-type: none"> • Compile accessible report • Present findings and recommendations to Associate Education Minister and presentation at conferences • The ending of the research study, and what next? 		

Table 1: Phased research approach diagram

The research team

Maguire (1993) undertook her emancipatory research as a doctoral student. She argued that, within this style of research, there is a need to build relationships, so the researcher cannot remain detached: “I was never a detached social scientist. I became involved in the women’s lives and they in mine, on a day-to-day basis, not simply during ‘project time’” (p. 175). I considered, as Maguire did, that my relationship with Andrew and Caroline and the participants would become entwined in and out of the research study itself.

Once Andrew, Caroline and I had decided to work as a team, there were a number of issues to resolve. Firstly, we agreed on a protocol for the team as to how we would work together (Table 2). This was agreed after looking at Bigsby and Frawley's (2010) research that provided "tips for being a co-researcher" compiled by a person with learning disability.

Research Team Protocol
<ul style="list-style-type: none"> • Listen to each other
<ul style="list-style-type: none"> • Respect what we each say
<ul style="list-style-type: none"> • What we say is between us
<ul style="list-style-type: none"> • Learn from each other
<ul style="list-style-type: none"> • Make decisions together
<ul style="list-style-type: none"> • Meet on a regular basis as agreed by the team
<ul style="list-style-type: none"> • Audio record team meetings

Table 2: Research team easy read protocol

This included, among other items, agreeing to record some team meetings and a code of conduct on respecting each other's views and confidentiality. We were very used to the teacher/student relationship at this stage, and this was an opportunity that would begin changing the dynamics of how we worked together. There was no doubt that Caroline and Andrew considered our friendship to be an important part of any ongoing relationship. Our acceptance as friends was important to them and I valued this aspect of the relationship, as manifested in our meeting socially outside of the research. The personal was as important as the professional because it represented the significance of being valued as people and not as individuals with learning disability. This was an important aspect of the research journey and goes some way towards defining the commitment required by not only practitioner researchers, but also academics and others when conducting this form of participatory research with young people with learning disability. There is a requirement to commit on a

personal, social and emotional level in order for young people with learning disability to feel an ethic of care and have trust in the researcher without disability. It also marks the beginning of the emancipatory journey necessary to change the power relationships in research. It placed huge responsibility on me as the researcher without disability, not only during the period of the research but, crucially, after it's ending (see for instance, Carlson, 2010).

The payment of co-researchers is an important consideration in participatory research, as highlighted by Burke, McMillan, Cummins & Wright (2003) and by Walmsley and Johnson (2003), who identified it as an ethical issue. In line with the latest developments in co-researching among people with and without learning disability, Andrew and Caroline were paid for their work on the study. Both received contracts as research assistants with the university but were paid with money from the HRC PhD scholarship awarded. They were paid on an hourly rate. Being paid an hourly rate was a double-edged sword; it had the advantage of not being dictated by the university funding constraints, but in some ways abdicated the university's responsibility for directly paying Andrew and Caroline.

Initial period of training

In considering the initial period of training, it is important for me to recognise that this time was as important for me to learn as it was for Andrew and Caroline. I had an opportunity during these few weeks to not only consider what Andrew and Caroline required in relation to learning research skills but also how I could learn to support them as best I could (Walmsley, 2004). I saw this as a situation where we learnt together, taking different things from the activities. Turner and Beresford (2005) consider training an important aspect when working with people with learning disability in participatory research. The Carlisle People First Research Group (2004) in the United Kingdom found in their study that there were a lot of research skills to learn. Drawing on the work of Lewis, Newton and Vials (2008), Perry and Felce (2004) and Mactavish, Mahon and Lutifiyya (2000), we embarked on an exploration of our strengths and areas for development during the initial period of training. 12 training sessions over a period of 6 weeks were held at the beginning of the project to establish basic research knowledge and terminology and to develop a shared understanding of what our research aims and questions were. This proved invaluable in creating clarity about our research aims to improve post-school outcomes for students with learning disability and

to understand what kind of life young people with learning disability want when they leave school. Andrew and Caroline were clear about “helping their friends” to “get to go to college” and “help people get real jobs.” Our team also discussed what a good life meant to each co-researcher, as a framework for data collection and ongoing analysis. Themes for a good life for Andrew and Caroline were framed in terms of relational aspects – including “family,” “friends” and “helping others” – and material themes such as “a job,” “college” and “money to do things.”

Andrew and Caroline had good communication skills and were both able to read and write most information. To achieve greater understanding of research language and terminology, we focused on new research words each training session and discussed their meanings. This was a similar process to research conducted by Butler, Cresswell, Giatras and Tuffrey-Wijne (2012) involving people with learning disability and using focus groups. In this way, we began to build up a vocabulary of research words and their meanings. Andrew and Caroline recorded the words and their meanings in their research diaries for reference. The words discussed are shown in Figure 3.

Research, qualitative research, quantitative research, participatory research, methodology, research design, ethics, methods, data, data collection, data analysis, participants, focus groups, questionnaires, sample, themes, content analysis, reliability, patterns, theory, interview, power, mentor, supervisor

Figure 3: Research vocabulary

We also used accessible websites as a source for information on research with people with disability (see, for instance, www.bild.org.uk). It was difficult to know how much understanding of research terminology was required, as this area is under-researched, but in our study it was premised on three things:

- whether Andrew and Caroline had requested a meaning
- whether or not I could explain the term in plain language (if I couldn’t, then it wasn’t worth using)
- if we needed it for our plain language recording, reporting and analysis

During the data collection phase, Andrew and Caroline co-conducted all the focus groups, and we pre-arranged to take it in turns introducing the sessions and asking the research questions. We also had the support of a graphic illustrator, cue cards and note-taker, and all sessions were digitally recorded. Anecdotally, I found that our ability to create a relaxed but focused environment for the sessions varied. Andrew and I were generally more successful, but this was defined by the strength of our personality, not whether we had an impairment or not (Perry & Felce, 2004).

It was also important to identify and clarify the roles of the co-researchers within the team as a tool for shifting power and because of desire for greater efficiency (Dalton & McVilly, 2004; Gilbert, 2004). This was initially done through a session where we identified our strengths and needs in order to assign roles. We all agreed that Caroline was a well-organised person and that she should do the agenda for team meetings and take basic minutes. The agenda items for the next meeting were always discussed at the end of the previous meeting so we could all contribute and Caroline would word process them. Andrew's strength was being a real "people person" with a good sense of humour and natural empathy with people. He proved adept in the focus group discussions in prompting the more unresponsive participants to be more forthcoming and also in framing a positive view of our research to people.

Andrew and Caroline viewed me as the lead researcher, and I would argue that this reflects the differing roles any team has. It is also reinforced by the research process, as ethics approval, progress reporting to funding bodies and other obligations reinforce this situation. What is important is that the research team approach in acknowledging different positions and roles was intended to recognise the individual capabilities and unique contribution of each person. My lead role was to create the environment where Andrew and Caroline could recognise and maximise their own capacity and capability to demonstrate leadership.

I recognise the dilemmas with this form of participatory research and the potential for my dominance and their vulnerability (Booth, 1998), as well as the dangers of tokenism (Walmsley, 1995). Capacity to undertake research has been often used informally or unintentionally – or, indeed, intentionally – as an excuse for not meaningfully including

people with learning disability. Andrew and Caroline had natural supports around them in their mentor, parents, friends and family to ensure there was integrity in our dealings.

A question I was mindful of concerned whose narratives were being heard through the research process. All three of us had different motivations and goals as co-researchers, which I did not consider to be a problem. Andrew and Caroline and I co-presented a paper on the early stages of our research at the New Zealand Association for the Study of Intellectual Disability (NZASID) conference in Hamilton in August 2009. A technique we employed with our presentation was to first display a PowerPoint presentation to set the research aims, questions and origins. We then used a “research team discussion” to explore the ethical, procedural and methodological issues that were arising (reported in Chapter 7). In doing so, we were taking a journey into the unknown, as none of us had rehearsed or knew what we would say, but we just talked to some basic questions on the themes. It proved a valuable technique in helping to gather real insight into how Andrew and Caroline viewed the research project, their role in it and increased status as a result.

Mentoring

In order to mediate, mitigate and confront the power of the professional and to provide support for Andrew and Caroline a mentor was approached who had a good deal of experience of working and mentoring people in the disability sector, as well as a lived experience in having a physical impairment. In discussing suitable people to fulfil this role, it was Andrew and Caroline who decided upon this person, as they had been involved as research participants with him through the Wayne Francis Charitable Trust transition project. This provided support for Andrew and Caroline to talk with someone independently about any issues or concerns they might have with the research project, including those concerning myself. The idea for a mentor arose from a discussion at a research team meeting when we were talking about my PhD supervisor and how I was able to get support and guidance from her. My lead supervisor also met with Andrew and Caroline as co-researchers in the project, to begin to gain an understanding of the personalities, motivations and perspectives we each contributed to the research. This was the first of many such occasions, not only at university but also at conferences we presented at.

Recruitment process for participants

User group views are prominent with regard to people with moderate or mild learning disability, and this is reflected in research (see, for instance, Begley, 2000; Costley, 2000). The participants in this study mostly fell within a moderate to severe group, with one student participant and two young adult participants who had very few spoken words and communicated with single word utterances, gesture and signing. This provided particular challenges for the research team in designing appropriate and effective means of accessing their views, a process which is detailed in later sections. The research aim, methodological position and substantive questions heavily influenced the selection process, meaning that we needed to meet and communicate directly with students and young people with learning disability who were still at school or had left in recent years.

The sample

Purposive sampling strategy

A purposive sampling strategy was adopted. Embedded in this was the idea that who a person is and where that person is located within a group is important, unlike other forms of research where people are viewed as essentially interchangeable. It was decided by the research team from the beginning that all information provided to the young people with learning disability had to be in plain language, with the use of symbols and pictures where appropriate. This was a very time consuming process and had to be taken into consideration. Having Andrew and Caroline to advise ensured a more user-friendly format was utilised.

Student recruitment

This sampling strategy was used to engage participants from five local schools, which were all members of a teachers' transition support network set up in 2007 as a vehicle for supporting secondary school teachers with responsibility for transitioning students. This proved useful in gaining access to the participants as we knew that the significant majority of students with learning disability attended these schools, either in a special school, mainstream unit or mainstreamed setting. The criteria for the sample were based on recruiting students

who were mostly – but not entirely – Ongoing Resourcing Scheme (ORS) funded with a recognised learning disability and who were in their transition from school programme. Table 3 illustrates the criteria used to recruit student participants and was formalised from discussion at a team meeting.

Currently in full-time education
In their last two years of school
Currently attending either special school, secondary school special needs unit, learning support or mainstreamed
Either ORS or non ORS funded and recognised by schools as having an learning disability
Recognised as in need of support with their transition to post school
Gender and cultural representation

Table 3: Student participant recruitment criteria

Having worked with many of the teachers through the secondary schools teacher support group, I was aware of the approximate numbers of students who were in their last two years of schooling and was fairly confident we would get a representative sample. Letters of introduction were initially sent to teachers and school principals in the support group detailing the project. The research team members then visited each school and spoke directly with potential participants about the research and its aims, using a PowerPoint presentation that included plain language, symbols and photos with a follow-up discussion. At the end of each visit, all students present were given information about the project, with consent forms to take home to parents or caregivers (Appendix A). Having Andrew and Caroline co-present the information to the potential student participants was well received by the students. This was evident from the way students directed many questions specifically at Andrew and Caroline about the research. Some staff were evidently surprised they were co-researchers. Students that expressed interest returned the forms to school to be passed on or posted them directly to us in the prepaid envelope along with the parent consent forms. This resulted in 14

students registering. This was a large focus group membership, but we felt duty-bound to retain the number, particularly as it gave us the representative sample.

Young adult recruitment

Recruitment of young adults was more problematic, as the nature of this group of young people meant that it was harder to gain access. Anecdotally, I was aware that many young people with learning disability, particularly those with moderate learning disability, were hard to track down after leaving school, as there was no formal system for tracking their whereabouts. Schools do not generally keep records on their student leavers with learning disability. One young man was approached through a friend of a parent who knew he was sitting at home with very little activity during the day. However, we knew the local vocational day services would be the pathway for most. Andrew and Caroline aided the recruitment process for fair representation by suggesting that we approach the Upp Club, a local youth club affiliated with the New Zealand Down Syndrome Society, as they were both members and attended the youth club fortnightly. Caroline also suggested that we approach a local tertiary provider to recruit students on the full-time, two-year Workskills course that she was enrolled on after leaving school. Andrew suggested his vocational day service would also provide a possible source of participants. This ultimately provided us with a fair representation of young people with learning disability who had left school in the last five years.

A similar process was undertaken to that used with the student group. We visited the three venues and spoke with the young people before handing out accessible information concerning the study and consent forms (see appendices A, A1). The young adults also took letters inform parents/caregivers and support workers as they felt appropriate. This provided us with 12 participants in all for the two focus groups, a large number that would be difficult to manage in a single focus group. There was no doubt that having Andrew and Caroline as co-researchers aided the recruitment process for both groups and provided added legitimacy to the study from the young people's perspective. Table 4 illustrates the criteria used to recruit young adult participants.

Recognised as having an learning disability
Having left special or mainstream school in the last five years
Gender and cultural representation

Table 1: Young adult participant recruitment criteria

Obtaining informed consent

Obtaining voluntary, informed consent from people with learning disability involves important ethical considerations because of their vulnerabilities. People with learning disability have fewer opportunities to acquire ordinary knowledge. They often have a reduced vocabulary and difficulty with abstract concepts (Bray, 1998; Finlay & Lyons, 2001). Because of this, words such as “confidentiality” and “anonymity” were carefully explained with the added support of symbols and photos. We took time to explain the nature of research in general, as well as the details of our specific research. Andrew and Caroline were often able to explain the research using words that I had not considered. The need for consent is distinct from the need for assent (Whitehurst, 2006) and often researchers will involve people who know the person with learning disability in order to establish both. Drawing from this literature, we obtained consent from the students and their parents or caregivers. We also followed this consent process for the young adult participants. Although most students were over 18 years, as were the young adults, a blanket decision was made.

People with learning disability frequently acquiesce to the requests of those perceived to be in authority (Bray, 1998). We took time to establish rapport with the possible participants prior to requesting their participation. This was achieved by going out and speaking with the different groups prior to obtaining consent. Again, Andrew and Caroline aided this process by acting as both a peer and a researcher to the participants. In aligning with the recent developments in obtaining ongoing informed consent from people with learning disability (Brookes, Archibald, McInnes, Cross, Daniel, & Johnson, 2012), my previous research experience (Gladstone, 2005; Cleland et al., 2008) and relevant literature, the following techniques were utilised:

- piloting the instrument

- topic guide/questioning route, including key and prompt questions
- use of graphic illustrator
- concrete visual cues (cue cards)
- use of symbols, photos and key words
- use of different types of questions to identify potential acquiescence
- alternating the sequence of responses to reduce response bias
- repeating responses back for member checking

When doing research that involves more than one interaction with participants, informed consent is more appropriately viewed as a process, rather than a one-time initial event. The strategy of “ongoing consent” offers opportunities for making better-informed choices regarding participation and decisions for withdrawing (Knox, Mok, & Parmenter, 2000). For this reason, we adopted an on-going consent process based on the following:

- Initial visit to talk with potential participants, explain the research and hand out information and consent forms.
- Obtained consent forms were revisited at first focus group and consent was again asked for.
- Consent forms were revisited at the beginning of each focus group.

The participants were assured of their privacy during and after the conclusion of the project. All identifying information remained confidential to the co-researchers, my supervisors and the typist or transcriber. All participants remained anonymous. All participants received a copy of plain language and accessible reports.

Data collection

It has become customary to use the term “data” to describe the accounts gathered by qualitative researchers (Polkinghorne, 2005). In order to fully initiate our participants into the

data collection process, a number of strategies were employed. Utilising the capabilities and lived experiences of young people with learning disability as co-researchers and members of a research team was paramount. This was especially important when working with participants who did not use a lot of spoken language in their communication (Biklen & Moseley, 1988).

The key method used to gather data was semi-structured focus groups, with a semi-structured questionnaire for obtaining demographic information and supporting data to cross-check emergent themes. A paired interview technique was used with two young adult participants attending a vocation day service as a compromise when we were unable to schedule them for the focus groups because of illness and holiday, and also as another research instrument to improve validity. Other important tools used were research team member diaries, recordings of research team meetings, email and text messages between research team members and video recording of a research team conference presentation at the ASID conference in Brisbane, Australia, in 2010. Three focus groups were held over a period of 15 months with students with learning disability. Two focus groups were held over a period of a year with young adults with learning disability who had left school. This allowed the research team to refine the questions from each focus group in response to the emergent data.

The utility of focus groups

In this section, I deal with the rationale, use and description of focus groups for the study, as these were the key data collection instrument. The utility of focus groups as a qualitative research strategy is relevant because of its social constructionist perspective of reality (Kaehne & O'Connell, 2010). The views and perceptions of participants become the data that produce a cumulative view of reality through discussion and debate. Focus group methodology is useful for obtaining lived experiences, not least by its active participation by people.

Krueger and Casey (2000) defined a focus group as “a carefully planned series of discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment” (p. 2). Robinson (1999) describes focus groups as having important advantages in the dynamics present and the outcomes that can be achieved when attempting to gain

insights into the views of any group of people. Focus groups have been found to be useful when working with people who have traditionally been perceived as lacking power and influence (Morgan & Krueger, 1993). They have also been used effectively with people who have different impairments (see, for instance Kerr, Cunningham-Burley, & Amos, 1997).

The use of focus groups when working specifically with people with learning disability is well established in the social research field (see, for instance, Barr, McConkey, & McConaghie, 2003; Barrett & Kirk, 2000; Bollard, 2003; Butler, Cresswell, Giatras, & Tuffrey-Wijne, 2012; Ippoliti, Peppey, & Depoy, 1994; Kaehne & O'Connell, 2010; Kitzinger, 1994; Krueger & Casey, 2000; Mactavish et al., 2000; McCallion & McCarron, 2004; Nind, 2008; Perry & Felce, 2004). Kaehne and O'Connell (2010), in their recent review of the literature for using focus groups in learning disability research, suggest that “focus groups allow participants to feel relaxed, develop a sense of ownership of the discussion and increase the potential to explore topics from different angles” (p. 133). Of particular importance to our study was the utility of focus groups with people with learning disability to create dialogue, as found in research by Cambridge and McCarthy (2001) and Barr, McConkey and McConaghie (2003). I was guided by their work in how focus groups can attend to the emotional aspects and potentially:

- help participants to gain confidence
- create safe, non-threatening and non-intimidating environments for discussion
- provide for group solidarity, peer support and validation of views and experiences
- enable members to participate in research from which they would otherwise be excluded due to poor communication skills

Focus groups are distinct in that they are not intended to obtain mutually agreed decisions but as a way of “listening to people and learning from them” (Morgan, 1998, p. 9). A particularly useful benefit of focus group discussions, as outlined by Morgan (1998), is when there may be a gap between people's perspectives, such as when professionals and students are involved. Having Andrew and Caroline co-facilitating the focus groups helped to bridge the potential gap between the young people and me as the “expert.” The interactions between people with learning disability in a focus group can be promoted through its inherent safe,

supportive and empathetic environment (Cambridge & McCarthy, 2001). However, it needs to be carefully managed so that clear guidelines and protocols are in place to ensure participants feel confident to contribute. The type of support offered to participants in focus groups can be guided by more than one philosophy and can be both facilitative and restrictive (see, for instance, Goodley 1998). This might be seen in the views and perspectives of the young people with learning disability being misinterpreted or hindered by, for example, a support worker “speaking” on their behalf. Kaehne and O’Connell comment on the ambiguities in learning disability research on focus groups with little actual detail or description and call for direct quotations to be used (2010, p. 138). I provide such detail in the next sections.

It is generally acknowledged in the learning disability literature that the ability to communicate is a significant barrier to successfully conducting focus groups (Kaehne & O’Connell, 2010; Kiernan, 1999; Prosser & Bromley, 1998; Stalker, 1998). Having Andrew and Caroline involved as co-researchers went some way towards mitigating this finding. I believe they did so by their nuanced understanding of how their peers communicated. I consider my thirty years of teaching in the field of learning disability to have provided me with greater practical knowledge and skills than the traditional or academic researcher. Together we were an effective team. Additionally, the design of the focus group instrument also aided the communication process and is described in detail later in this chapter.

The time-saving advantages of focus groups by interviewing more than one person at the same time are relevant, as found by Fraser and Fraser (2001). My prior work using focus groups with students and young people with learning disability (Cleland et al., 2008; Gladstone, 2005) showed that participants tend to feel supported by the group dynamic and are more likely to share their opinions with other people if they can identify with them (Farquahar with Das, 1999, p. 47). An advantage of the focus group that is absent in other survey data collection methods is the use of prompts. These were a particular feature of our focus groups and encouraged participants to elaborate upon their own ideas and responses, thus providing additional information or clarifying points made. The prompts used were verbal question prompts, gestures, symbol cards and graphic illustrations.

The skills and understandings each of us as co-researchers brought to the focus groups were significant. Having a research team comprised of young people with learning disability demonstrated that young people with learning disability could take a leadership role in the research. It provided opportunities for the participants to identify with one or more of the interviewers and consequently feel less anxious. It also allowed for the potential of my influence over proceedings to be reduced.

Individual personalities are a significant factor when interviewing in any form and influences participant responses. To support the collaborative nature of the focus groups, Andrew, Caroline and I shared the asking of the questions and probe questions. However, it was not until the second and third focus group that Andrew and Caroline began to ask the probe questions. There can be no doubt that my life's experience as a teacher, researcher and empathetic and lively personality had a strong influence over the focus groups. This could be said to have had negative and positive influences on the data collected. To mitigate this and promote Andrew and Caroline's input, we put in place some strategies. After the first focus group, we talked about how Andrew and Caroline would welcome participants and introduce each session. Learning from the first focus group with students, we created a schedule of questions with the name of who would ask which probes. I found it extremely hard to stop myself following up or repeating a question that Andrew or Caroline had asked. Likewise, I would interject if I thought Andrew or Caroline were not eliciting a response that I knew could be there in the discussion if the correct pause or prompt was offered. This demonstrated my ingrained paternalistic and professional biases, which I was aware that I had to resist and unlearn. With each focus group held, Andrew and Caroline became more confident and aware of facilitating the process, and I became more adept at stepping back. In this way, Andrew and Caroline gained specific skills – such as when to pause and when to prompt – directly related to this method of data collection.

The importance of speaking clearly and slowly using plain language, and also repeating responses, cannot be underestimated in working with the young people in our study. Also crucial was the intentional use of pause and prompt to elicit responses. As a qualified sign language teacher, I was also able to utilise signing as another tool for participants to access the questions.

Interviewing the same students three times and young adults twice enabled us to explore whether perceptions, attitudes and experiences changed over time. The fact that we met multiple times with the two sample groups allowed for a relationship to develop and evolve. This was an intentional strategy, in that we were embedding notions of care, trustworthiness and reciprocity to create an environment where people felt valued and able to be themselves and offer insight into their lives. Knowing many of the participants prior to the focus groups supported data collection. Some of the participants were from the same schools and others had met through interschool sports events or social clubs and activities. Many of the student participants knew me as a teacher, as well as through these cross-school activities. Speaking to the same group of young people more than once allowed us to evolve and refine questions from the previous focus group as a result of initial and ongoing analysis of the data.

Researchers differ with regard to the optimum size of the focus group. Some say there should ideally be five to six in each focus group, because if the group is too large participants with learning disability may find it difficult to take part. This might be because of a fear of speaking out in a crowd or differing modes of communicating (Barrett & Kirk, 2000; Fraser & Fraser, 2000). Fraser and Fraser (2000) found that where communication difficulties were present, small groups were needed to achieve better results (p. 228). However, larger groups have been used successfully when holding focus groups (see, for instance, Andre-Barron, Strydom, & Hassiotis, 2008). I felt group size was a combination of participants' forms of communication, the environment and the skills of the facilitators.

We found that heterogeneity within the group meant different views were expressed, and consequently there was more discussion on issues that arose from the questions. In this way, a kind of momentum was generated that allowed underlying opinions, meanings, feelings, attitudes and beliefs to emerge alongside the descriptions of individual experiences. I feel this was also generated by the relaxed but focused environment Andrew, Caroline and I created.

A pilot focus group was held with students at the special school where I worked prior to beginning the student focus groups. This provided a useful run through for all the co-researchers and also enabled us to test the venue, protocol, question schedule, note-taker and use of technology. As a result of this pilot, we decided to engage a graphic illustrator to aid the process, and we also simplified the symbols and words on the PowerPoint.

Reliability of data

In judging the reliability of the data from the focus groups, I was conscious of a number of factors that needed to be taken into account with our research participants, as outlined by Davis, Watson and Cunningham-Burley (2000) and Dockrell, Lewis and Lindsay (2000). These were the mode and type of communication, context and support materials; the perceived and actual role of the interviewer; pace and structure of the focus groups; physical arrangements and built environment; the use of groups and individuals; the importance of “no” responses; and methods of recording. As a research team, we discussed how we would address concerns by devising a protocol for the focus groups (see Table 5),

Focus groups of student participants

There were 14 students in the first focus group from five schools, including two special and three regular secondary schools. 10 of the 14 students were from the two special schools, three students were from units, and one was in a learning support class within a regular secondary school. 13 of the student group remained for the second focus group, with 11 for the third. One student was ill for the second focus group, with that young person being ill again for the third, and two students had left school by the third group. The students were aged from 16 to 20 years, with 6 female and eight male students. All focus groups were held during the school day. The focus group participants were able to take turns in contributing, and that enabled participants to “collectivise” their personal experiences. We needed to take into account the most effective ways to access the participants’ views, considering their comprehension levels, motivations, ages and favoured modes of communication (Lewis & Lindsay, 2000). The student participants used differing modes of communication. Nine used spoken language, three used a combination of signing and spoken language, and two had few spoken words and used sign language. One of the three students who dropped out after the first focus group was non-verbal. Two of the students had teacher assistants to support them with their transition into this new environment. The assistants also provided some interpretation of the students’ responses when it was unclear what they were communicating. This was discouraged, except to repeat the student’s utterance, sign or gesture in spoken words. It was important that the teacher assistants were there only to support participants’

active participation and not to speak for them. The teacher assistants remained the same for all three focus groups.

Focus groups of young adult participants

12 young adult participants attended, with 10 of that number attending a local vocation service (two part-time and eight full-time); one attending a full-time, two year discrete tertiary course; and one undertaking an individualised programme from home including some form of part-time employment. Their ages ranged from 19 to 26 years, with seven male and five females participants. As nine of the participants were also members of the Upp Club, it was decided to hold the focus groups at this venue for its familiarity. The venue layout was similar to the student focus group but differed in that there was no use of PowerPoint due to technical difficulties. The venue was bigger, being a hall, and there was a certain amount of distraction from other side rooms. The young adult focus group had two support workers present, as well as the Upp Club manager; these attendees remained the same for both sessions. Both sessions were held in the evening. Nine young people used spoken language only, two used spoken language and signing, and one was non-verbal and used limited signing. The young adult who was non-verbal had one of the support workers sitting next to them.

Elements of the focus group instrument

The focus group environment was deliberately arranged to provide a sense of calm and a relaxed atmosphere. At the suggestion of Andrew and Caroline, student focus groups were held in a room on the site of one of the special schools, as the majority of participants were familiar with it. In both student and young adult focus groups, the room was large enough to fit everyone in, with comfortable chairs arranged in a semi-circle around the three co-researchers. The note-taker was sitting at a small desk to the right of and slightly behind the co-researchers so that she could observe use of gestures and sign language as well as see the faces of all the participants. When used, the PowerPoint was displayed on the wall behind the co-researchers, and the graphic illustrator was positioned with a flipchart to the left of and behind the co-researchers. The digital recorder was placed on a small box in the middle of the semi-circle of participants. This layout provided the most effective environment for easy

group discussion while promoting accessibility to the key discussion points (see Figure 4 below).

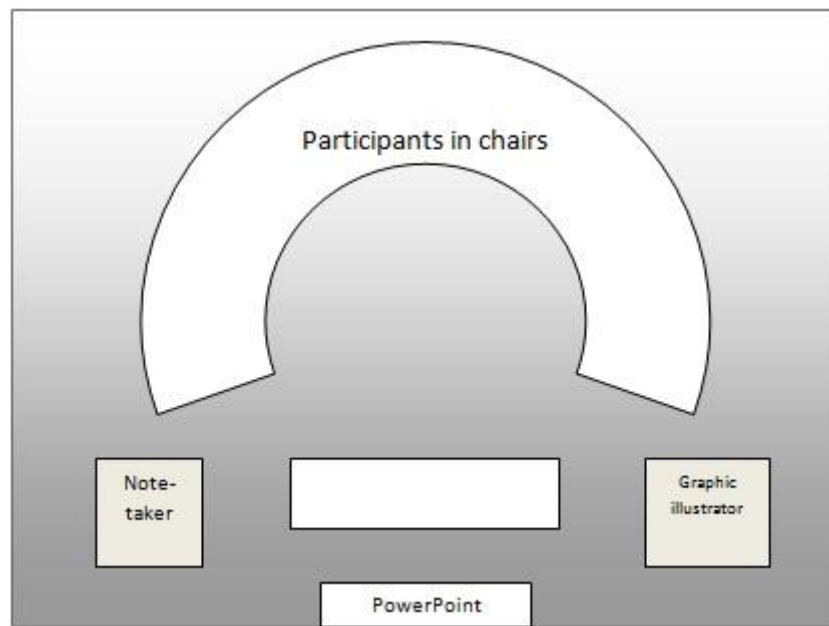


Figure 4: Focus group room layout

The organisation and environment created by the carefully considered layout and actions of the co-researchers created a space for the participants to tell their stories.

I now deal with each of the research instrument elements:

- Roles for research team members
- Protocol for sessions
- Use of note-taker
- Use of technology: digital recording and PowerPoint
- Use of graphic illustrator
- Use of cue cards
- Role of support staff

- Venue and environment

Roles for research team members

As already discussed, we attempted to share the focus group facilitation. Although I believe it did not unduly influence the raw data there was no doubt that Andrew, Caroline and I would have benefited from a greater appreciation of how much I would influence the questioning schedule and focus group in general. Each new focus group saw Andrew and Caroline becoming more confident and skilled as facilitators and beginning to use the strategies of prompt and pause in receiving and judging the quality of responses to the questions. The questioning schedule was delivered with Andrew or Caroline always starting and finishing the schedule. Although Andrew introduced the second student focus group, I generally elaborated with more detail and introduced the other focus groups. All three of us had our own copies of the questioning schedule with our names next to our specific questions. We also had an “ice-breaker” question before starting the question trail, which was designed to relax and induct the participants into the session. The question was: “If you could go out for dinner with someone famous, who would it be?” This generally produced an enthusiastic response and got the sessions off to a positive start.

Protocol for sessions

The protocol followed common guidelines and was used to provide guidance and set boundaries for the sessions. The sessions took approximately two and half hours each, with refreshments halfway through. Towards the end of the sessions, the participant’s attention and focus was waning. A PowerPoint slideshow was used to display a plain language/photo/symbol version of the protocol. All participants had completed their consent form prior to attending the focus groups and, in keeping with the ongoing consent process, participants were asked at each session whether they wanted to take part and told that they could withdraw at any time. The protocol was designed through discussion with the co-researchers at a team meeting and shown below:

Focus Group Protocol – Students and Young adults (to be talked through at beginning of all sessions)

1. Provide people with name tags.

2. Welcome people and explain the purpose of the project:

We want to look at what kind of life you want and what you think is important for a good life

Request consent to participate again.

3. Introductions

Explain our different roles – facilitators, note-taker, and graphic illustrator to draw pictures of what we say.

Warm Up Exercise: Tell us about someone you would like to invite to dinner and why.

4. Key Points: Go over format for today.

(a) The group will be talking about what kind of life you want and what you think is important to have a good life.

(b) You will be asked some questions.

(c) Someone will write down what people say and someone will draw what you say.

(d) The ideas of the group will be talked about with other people, but your name will not be used.

(e) You can decide if you want to take part in the group.

(f) You only need to answer the questions that you want to.

(g) Talking at the group will not have a bad effect on you or anyone else

(h) During the focus group you can:

- Ask for questions to be said again and to
- Stop the focus group at any time if you need to go to the toilet, have a drink or food.
- Ask any questions.
- Ask for any help.

5. Ground Rules – on POWERPOINT

- Are you ok with these ground rules?
- Are there any other ground rules that you would like us to have?

6. Talk about “house-keeping” details: toilets, emergency procedures, available support, etc

Table 2: Protocol for focus group sessions

Use of note-taker

A note-taker was present for all the focus groups and wrote freehand on a writing pad. She then typed up the notes. The use of a note-taker was particularly useful as a resource for Andrew, Caroline and I to have a reasonably accessible summary and gain a quick understanding of the key responses. The note-taker had also been the note-taker for the focus groups in the Wayne Francis Charitable Trust transition research (Cleland et al., 2008). Her

previous experience in that research was valuable to us and supported the process of data analysis.

Use of technology: Digital recording and PowerPoint

The use of technology was useful for assisting the focus group on many levels and has been used in similar research (Seymour, Bellamy, Gott, Ahmedzai & Clark, 2002). An easy-read PowerPoint slide presentation was used at the beginning of each student session to outline the aims and the protocol for the focus group. The PowerPoint utilised photos, symbols and key words to convey the protocol. In the first student focus group, it was also used to display the questions. An Olympus DS30 digital voice recorder was used for all the focus groups and proved a very effective device, primarily because of its ability to reduce background noise while at the same time pick up the voices of the participants. Often, the participants' responses were very quiet, and the digital recorder was highly efficient at distinguishing between speech and ambient noise.

Use of graphic illustrator

The use of a graphic illustrator was a technique I had used effectively in previous research (Cleland et al., 2008). The graphic illustrator was a qualified graphic artist who had also taught and worked in the disability field. She used a flipchart and illustrated each question using one sheet of A0 white paper. She illustrated the key responses from each question on the sheet before taping it on the wall and moving onto the next sheet and question. In general, this worked well, but it did cause a degree of distraction when she was moving around and putting completed sheets up on the wall. Pictorial representation of the ideas and words was useful to recap and allow time for processing and far outweighed the distraction. Each sheet of illustrations was then photographed with a digital camera to be used for analysis (see Appendix E).

Use of cue cards

Lewis (2004) found question and answer formats may be more constraining than narratives or use of statements. This can be described as the dilemma between more structured research

instruments for obtaining the participant's views and the risk the data is then contaminated (Lewis, Newton, & Vials, 2008). Drawing from Lewis et al.'s research we used cue cards to facilitate eliciting views from the range of participants. It also provided "a structure which, while scaffolding elicitation processes and responses, do not constrain or bias" (Lewis et al., 2008, p. 27). In this way our use of cue cards added to the verbal cues. The cards had simple black and white symbols to help convey the meaning of the questions. The use of cue cards in the focus groups was not primarily used as a tool for reducing the co-researchers verbal questioning but as a support for it.

Role of support staff

In this research, there were teacher assistants and support workers who were present at all the focus groups. This was entirely based on a requirement to balance meaningful access to all the participants' views with the real possibility of obtaining the "proxy perspective." I considered research that discussed support workers, the different beliefs and discourses about learning disability they might hold (Goodley, 1998) and their influence on the primary participants (Llewellyn, 2009). To alleviate possible influence and bias, the focus group protocols prevented "secondary participants" (support workers) from speaking other than to directly interpret a communication from the primary participant they were supporting. Because the secondary participants, as with the teacher assistants, came from social constructionist or relational model perspectives, they knew from the beginning that there was never any expectation from them to "speak up" for their schools or services. The questioning route was clearly directed at the young people and their views. This was not finally an issue and I did not consider the data collected to have been unduly influenced.

Venue and environment

The venue and environment for the focus groups was an important factor in promoting a relaxed, friendly but motivating environment where the participants felt encouraged to give their views. As described earlier in this section, the venues for both groups were suggested by Andrew and Caroline at team meetings prior to data collection.

Questionnaire

Rose and Grosvenor (2001) stated:

Effective use of questionnaires in research are predicated upon careful deliberation about conceptual aims, the information that is required to fulfil these aims, the resources available, the population sample, type of questionnaire, questionnaire construction, the administration of the questionnaire and analysis of data collected. (p. 129)

A questionnaire (see Appendix F) was designed using a combination of plain language, symbols and photographs, as many young people with learning disability experience difficulties with reading conventional text and find it easier to comprehend symbols. This was the case with many of the participants in this study. Symbols have the ability to linger longer in the mind than the spoken word and can therefore be viewed and decoded at their own pace. Symbols can be used in combination with images (such as photographs and pictures) to express more complex concepts than it is possible to convey using arrays of objects and photographs alone.

The questionnaire was used mainly as a secondary data collection instrument to obtain demographic information and provide a baseline for the young people's views. Lewis (1995) referred to the need for children and young people with learning disability to be allowed to say or use "don't know" in questionnaires and interviews, as this reflects an emergent "voice." In acknowledging this and my previous research (Gladstone, 2005), a word/symbol reply combination was used that allowed the respondents to give a "don't know" reply. The differing representations of the mouth through the three replies allowed for a possible negative bias with the "No" reply to be minimised. It was felt that a mouth with its corners down might unintentionally give a negative image of "No"; therefore, the reply grid was designed as shown in Figure 5, with a neutral flat horizontal line for the "No" mouth.

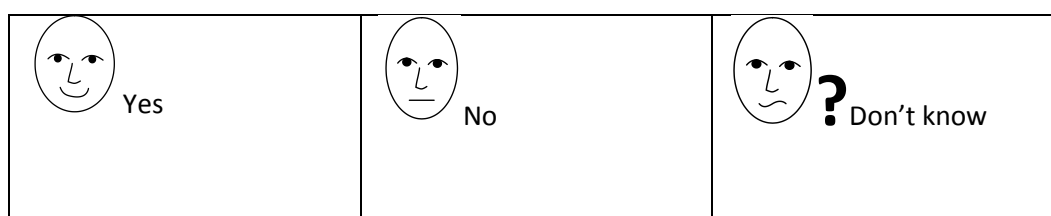


Figure 5: Reply grid

The questionnaires were completed by the student participants only, as there was not the time with the young adult group, and it was decided that sending them home with the young people for completion was unrealistic and open to contamination. All students had seen the questionnaire and been allowed to familiarise themselves with the layout and questions. Specific problematic words were discussed and explained. Each question was answered by using a pen to put an “X” against the appropriate reply. The questionnaire was useful as a method for checking the students’ views from the focus group and was completed at the end of the first focus group. The questionnaire data was mostly used for demographics and as a check with focus group data.

Co-researcher reflective diaries

In line with a constructionist epistemology (Crotty, 2005), we utilised research diaries as a method of collecting interpretive, reflective data (Alaszewski, 2006). From the beginning of the research period of training, we kept individual diaries as a way of recording our thoughts, particularly thoughts that might be lost if not recorded close to the time of the event. All three of us kept some form of diary or ongoing account through the project. I reinforced the importance of putting a date to all diary entries, which Andrew and Caroline became reliable with. When compiling and analysing the raw data from the diaries, the opportunity to clarify and explain entries was useful. Excerpts from our diaries are drawn upon in the findings chapters, particularly Chapter 7. From the beginning, I impressed upon Andrew and Caroline that keeping a diary would help to give them a better understanding of the research process and be useful in recalling specific events. Andrew and Caroline were both fairly confident writers and word processors – particularly Caroline, who kept a personal diary outside of the research project. We all used a combination of handwritten diaries and Microsoft Word to record. I also used the Notes application on my iPhone for diary entries, so I could record my thoughts at any time of the day and night. This proved a particularly useful way of recording immediately my thoughts, ideas and queries. I would then email each iPhone note to my laptop for reflection and analysis. The use of technology for data recording became an efficient and flexible tool. Having an electronic version of my whole research diary, formed from different applications and devices, was an innovative solution when working in and out of the research field.

Texts and emails

The use of information and communication technology (ICT) in this research project greatly aided the ability and efficiency of the co-researchers to communicate on a number of levels. This is described and illustrated in the findings chapters. Andrew and Caroline, as with the majority of their non-disabled peers, grew up in families where they had access to computers and mobile phones. School provided them with the learning and skills to take advantage of this technology for emailing and texting, which became important tools for communicating during the research.

Video recording of conference presentation

I requested a video recording of our joint presentation at the Australasian Society for Intellectual Disability (ASID) in Brisbane on September 30, 2010. The second half of the conference presentation was an open, unrehearsed discussion of the different elements that Andrew, Caroline and I had discussed at previous team meetings. I created a conceptual map of the different factors involved in working as a research team, which was put up as part of our presentation on our research findings. It provided an excellent tool for examining how we worked as a research team. Discussing the different factors in front of the conference audience proved a useful way of providing individual insights into working as a team and is further reported in Chapter 7.

Data collection timeline

The period of data collection began with the first team meeting at the beginning of October 2009 and continued through to November 2011. After being postponed twice, the findings report was eventually presented to the then-Associate Minister for Education, the Honourable Turiana Turia, on May 30, 2012.

The student and young adult focus groups and interview were held between February 2009 and December 2010. The initial period of training for the research team took place between October and December 2009.

Data collection was ongoing throughout the two year study through the recording of focus groups, some team meetings and the ASID conference, as well as electronic communications among the co-researchers via text and emails. There is a real dilemma, I believe, in this form of collaborative research when making decisions about what counts as data. I considered all communications that were recorded between the co-researchers and the participants, and also among the co-researchers, to be valuable data. This fulfilled two roles, allowing for an analysis of data from the focus groups on the one hand and an analysis of the research team relationship on the other.

Transcribing

A person was employed to do the initial transcribing of the focus groups which had been digitally recorded. I asked her to transcribe the recordings verbatim. After I had received each initial interview transcription, I then listened to the recording at the same time as reading the transcript, added anything that had been missed.

Before and after each focus group I wrote field notes that I included in my data analysis. These field notes recorded my thoughts and feelings about the focus groups. I found this useful, particularly after the first focus group, as a way of modifying and improving how each upcoming focus group was organised and run.

Data analysis

It is important at this stage to be overt in describing what involvement Andrew and Caroline had in the analysis of data. The literature on descriptive accounts of young people with learning disability and their exact involvement in the data analysis process is very limited, although over the last few of years this has begun to change (see for instance; Garbutt, 2009; Nind, 2013). This analysis process is as much about the democratisation of research as it is about empowerment and innovation in practice. In order to strive for deeper meaning I was always aware that we were “trying out” analysis as we went and learning on the job what worked best. There was much trial and error, but through the ongoing analysis process Andrew and Caroline became meaningfully involved in the process of meaning-making. The

prominent position of Andrew and Caroline as researchers in the eyes of the participants and with audiences at conferences supported the data analysis process.



Figure 6: Three-stage data analysis

A three-stage process was adopted for the data analysis (see Figure 6). First, the verbatim transcripts of the early team meetings and focus groups were thematically analysed by the co-researchers. Our study followed Bogdan and Taylor’s (1998) view of qualitative data analysis as not a mechanical or technical process but a process of inductive reasoning, thinking and theorising (p. 140). I was also guided by Yin’s (1989) suggestion of an approach that recognised the many stages involved – such as examining, categorising and theming – which allowed me to tackle the key aims of our study and keep them at the fore in the analysis of “what was going on” and the implications. Krueger & Casey (2000) added to this in suggesting that the purpose or aim should drive the analysis and that it should be systematic, sequential, verifiable and ongoing. With reference to specific literature on analysis and people with learning disability, I drew on the work of Nind (2008), Tuffrey-Wijne and Butler (2010) and Kramer, Kramer, Garcí’a-Iriarte and Hammel (2011). In following these perspectives and views, the aim of the qualitative analysis for this study was to bring meaning

to the lived experiences of young people with learning disability. Through the collaborative experiences of the research team process, we were striving for emancipatory practice. I adopted an approach to data analysis of “collaborative meaning-making” over an extended time.

We were using naturally occurring data for analysis, in that it was what was actually been said or heard or seen. This was important as it recognised the value of non-verbal communication like gesture, body language, pauses and silences. Of course, there is a certain degree of “contrived interaction” in naturally occurring data, but it doesn’t really matter because naturalness is not something specific to certain types of data and our data collection practices were not intrinsically natural or contrived Speer (2002). However, I would also acknowledge the influence of traditions in narrative analysis and is derivative, communication analysis (Williams, 2011). We were, between us, usually but not always aware of what was happening in the communication between participants – and, indeed, the communication between co-researchers and co-researchers and participants. We did attempt, though, to be sensitive to the non-verbal communications and interactions that were part of the focus group discussions. I chose not to become too immersed in communication analysis, instead using it to ensure that the “voice” of those participants with little speech was “heard.” The non-verbal data could be utilised for richer communication analysis in another study.

Our analysis of the focus group transcripts utilised the basic tenets of generic qualitative analysis (McLeod, 2001, pp. 130–160) and the processes of thematic analysis (Braun & Clarke, 2006; Gibson & Brown, 2009; Williams, 1999). Braun and Clarke (2006) describe thematic analysis as:

identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail. However, frequently it goes further than this, and interprets various aspects of the research topic. (p. 79)

Preliminary data categories were developed and organised according to the participants’ responses to the focus group questions. The research aims and questions guided the data analysis process.

In practice, a significant amount of time was spent on analysis, not only in team meetings but at home as well. We were conscious of the requirement for data protection. Andrew and

Caroline took transcription extracts of 2–3 pages of text home in files. In this way, Andrew and Caroline were able to analyse pieces of data on their own without my influence. Caroline, for example, used basic coding with coloured markers to highlight different key words and phrases she considered were emerging from the data as a strategy. We then discussed these key words and the themes that seemed to be emerging during the team meetings. These extracts were kept in research folders to be taken home. I felt confident that Andrew and Caroline understood the requirement to keep the data confidential. This was described by them as the “personal and the professional” responsibilities they had. This routine was yet another way of sharing ownership and responsibility and adopting a professional manner. The willingness of Andrew and Caroline to spend time outside of allotted team sessions on analysis provided rich data without my influence. It was through their unique, lived experience and our shared exploration of the meanings of the data that interpretations and therefore understandings, findings and implications slowly emerged.

The literature is very limited concerning descriptions of the actual process of involving young people with learning disability in the analytical stages of the research and how it is achieved (Tuffrey-Wijne & Butler, 2010). This meant I was to some extent in uncharted territory with how best to support the collaborative analysis process. The PAR approach meant that all co-researchers were involved in the ongoing form of analysis, which added to the complexity. I accepted that as lead investigator, I was responsible for ensuring Andrew and Caroline took an active role in the analysis of data. However, many times during our discussions concerning the search for meaning from the data, I learnt from Andrew and Caroline a “truer” meaning and a different interpretation of the data. My often clumsy attempts at trying to actively engage Andrew and Caroline in the process of data analysis floundered at times, albeit due to my lack of ingenuity and the ever-present issue of a lack of time rather than their capacity, capability or motivation. From the beginning, avoiding the use of jargon (Dowse, 2009) was something I was conscious of, with Andrew and Caroline and with the focus group participants. I balanced the use of research language with plain language wherever possible, both spoken (key words/phrases, gesture and expression) and written (key words, symbols and photos). This is a critical element in understanding and meaning-making when researching with young people with learning disability. As with the whole research process, I ensured we utilised a combination of symbols, pictures and words to strengthen access to data

analysis. In team meetings, we would often use the whiteboard to illustrate ideas about what the data were telling us.

Data analysis began from the early conversations on the aims and purpose of the research at the initial training sessions and team meetings. Our emergent understandings of each other as people, acknowledging and being always open to what we each brought to the team, provided the foundations on which to build a framework for the analysis. This early data was recorded (some audio taped team meetings) and documented (digital photos of whiteboard and research diary). The next key stage of the data analysis was to collect the focus group conversations and turn them into digital audio recordings, then take the nearly 11 hours of digital audio recordings collected from the three student and two young adult focus groups and transform them into written transcripts. Our data analysis did not take place in a linear fashion; instead, each part of the process overlapped another and went back and forth as new meanings and understandings emerged. During the process of analysis, it was often the case that data collection, transcribing and data analysis were happening concurrently. As a research team, we were “learning on the job,” as the process of analysing data from one focus group informed the questions for the next focus group. In this way, we sharpened the questions with each focus group, as well as between the student focus groups phase and the young adult focus groups. After the first student and young adult focus groups, the participants were provided with a plain language summary of the emergent findings at their next focus group to recap on what they had said and as a member check for data reliability.

There was a large amount of data collected through the flexible methods used. The analysis took three forms. One was the analysis of data from the focus groups and student questionnaire. The second was the analysis of data from the transcriptions of team meetings, the ASID conference video and the verbatim texts and emails among the co-researchers. The third was our research diaries, relevant literature and discussions. The analysis was going on simultaneously and each round of analysis informed the next.

We worked as a group and individually to analyse data. This approach had two benefits. It created an environment that encouraged debate and discussion, common among researchers analysing data. It also served as a form of member check in the supportive team environment. Andrew and Caroline knew they could make mistakes because I was constantly making them

and they were good at spotting them. This team analysis helped to equalise the inherent power imbalances often found in learning disability research (Walmsley, 2004).

Ours could be described as a multi-stage exploratory approach to the data analysis where – although both stages focused on responding to the overriding research aims and questions – there were bound to be differing interests, intentions and motivations among the research team members and in the analysis and findings from the participant focus groups. This was also a result of the organic and ongoing form of analysis this study took, where all data was potentially significant. I was conscious that this might mean a hierarchy of analysis and I accepted this as in some ways inevitable. However, I believe the shared research aim and always referring back to the research questions went some way towards balancing my unease at mostly leading the process of analysis.

Focus group analysis process

Familiarisation

We discussed the research aim and questions and what we were looking for against an initial analysis framework we designed together, laid out in Table 6 and further elaborated in Appendix J.

What are students doing at school?	What do students want to do after school?
What are young adults doing after school?	Why?
What is important to the students?	What is important to the young adults?
What helps?	What gets in the way?
Who helps?	Who gets in the way?

Table 6: Initial analysis framework

We then listened to excerpts of the audio recordings and used the transcribing foot pedal to stop the recording and write down on the whiteboard anything we thought was important. We

took a digital picture of all the words on the whiteboard for later analysis. The process of moving from research questions to sub themes and themes is shown in Appendices I and J.

Coding and identifying themes

First, I went through each focus group transcription with the note-taker's notes and the graphic illustrations (student focus groups), adding comments on my initial thoughts. The notes and graphic illustrations were then given to Andrew and Caroline with short half- page excerpts of the full transcriptions. They each looked through these sheets at team meetings and added their written comments, highlighting with marker pens words or groups of words/phrases they thought important. They also took this home in their own time. The analysis often happened concurrently, where I was constantly reading and re-reading the transcripts and joint notes outside of the team meetings. In this way, sorting the data into coding categories then emerged into the themes "what the young people want" and "what the young people got," with sub-themes that form the findings in Chapter 5.

As the focus groups were held and ongoing analysis occurred through discussion at team meetings, our understanding and my interpretation of the literature grew. Importantly, Andrew and Caroline did not have the interest and capacity to interrogate the literature

I then added more themes that demonstrated my deeper understanding about exclusion and the mechanisms of power. The opportunity to work with Andrew and Caroline through this period on both a professional and a growing personal relationship greatly enhanced my and our understanding. Bauman's metaphor of the stranger became a theme to position the young people in education and society, as presented in Chapter 6. Through the ongoing analysis process, an important theme emerged with Andrew's prophetic words – "it's all about relationships you know" – that became the "the relational dimension" and is presented as Chapter 7.

During the nearly 15-month focus group data collection and ongoing analysis period, I collected my own interpretations, listened attentively to Andrew and Caroline's thoughts, actions and how we related to each other and also reviewed the literature. My lead supervisor provided inspiration and guidance with new readings and new ways of seeing based on critical, relational and emancipatory pedagogies.

Dissemination

The process of Andrew, Caroline and I co-presenting our initial findings was a positive learning process for everyone involved: conference participants and us as presenters. During the study, we presented at three conferences and gave talks to numerous transition stakeholder groups. Crucially, Andrew and Caroline were beginning to realise through this process that their views were being recognised by people without disability as valid and expert. This realisation was emancipatory for them as their confidence grew with this recognition. Caroline was invited onto the board of the local People First organisation. Andrew and Caroline began to be viewed as “experts” to speak to on matters relating to people with learning disability. They were advocating for others with learning disability. As we presented our emergent findings, we were engaging in ongoing analysis through the relational dimension categories and themes we devised for how we collaborated as a research team, as illustrated in Figure 7. These themes were arrived at through ongoing conversations in team meetings (see also Appendix I for an example of how these themes were arrived at).

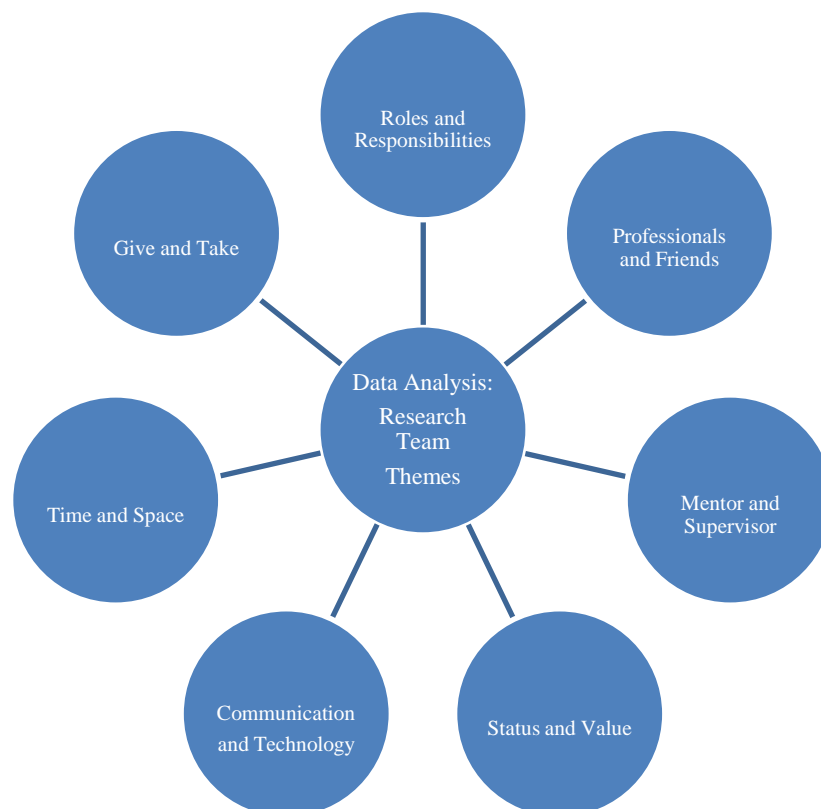


Figure 7: Data analysis of research team themes for how we collaborated

Rigour and credibility

The findings in this study are an authentic and trustworthy reflection of the description of the perspectives and lived experiences of the co-researchers and participants. Rigour refers to how strong a body of research, confirming that all procedures have been followed judiciously and that, as far as possible, all potential compromising factors have been removed so that any reader judges conclusions to be dependable or trustworthy. The trustworthiness of research is a way in which the competence, transparency and integrity of that research is shown. Our study utilised a framework developed by Lincoln and Guba (1985) for methodological rigour in qualitative research. This included credibility, transferability, dependability, confirmability and authenticity.

Credibility seeks to address the issue of “fit” between participants’ accounts and how they are represented by the researcher. I utilised member checking by continually returning to my co-researchers and participants to consult with them on whether descriptions provided were authentic. However, I also understood that we were all research participants and as such none of us were exclusive commentators on our actions. Another strategy I used in assuring credibility was my reflexive research diary, where all prejudices and biases could be “bracketed” in a way that would hopefully promote honesty and transparency. Reflexivity, according to Northway (2000), may be viewed as the critical gaze turned toward itself. Through prolonged and close engagement with Andrew and Caroline in the collection and analysis of data, I was able to obtain a richer breath of knowledge of the lived experiences of the young people with learning disability. I believe this also enhanced credibility.

Dependability concerns itself with the responsibility of researchers to substantiate that every part of the research is transparent, methodical and clearly documented (Lincoln & Guba, 1985). Through interacting closely with my co-researchers, doctoral supervisors and critical friends, and through presentation at conferences, I was able to seek dependability through ongoing discussions of methodological and analytical decisions throughout the research. This also strengthened the confirmability of our study in the understanding that data produced was not exaggerated or fabricated.

Conclusions from our study were considered in the light of whether they could be transferred to another context or group – in other words, whether they could be generalised (Lincoln &

Guba, 1985). Transferability, as opposed to applicability of a study, means that a body of research's findings can "fit" into other contexts outside the study situation, where readers regard findings as meaningful and find it applicable within their own contexts and experiences. I sought to furnish enough descriptive data in our study so that others may evaluate the applicability of data to other contexts and settings. In this way, for example, ensuring easy-read versions were available was an important part of the process.

Ethics

Issues of relationship

By the nature of our study and its origins in the student–teacher relationship in a school, this research was in many ways predetermined to be relational. The relational dynamic was overt in the approach adopted because Andrew, Caroline and I had the same goal of improving post-school outcomes for their friends and peers labelled with learning disability. I came together with Andrew and Caroline to form a research team. The relationship we developed and nurtured over an extended period is defined by action. The action approach takes longer because it naturally takes time to build relationships, to build the mutual trust, reciprocity and risk required for sustainable change in terms of setting and context. The insider/outsider dynamic was fluid in nature because we shifted through settings and contexts, going from students and teacher to co-researchers to friends to people trying to live our day-to-day lives. We were all involved in the setting and context of the transition process from school. Our relationship defined the success of the research. This success was defined by how Andrew, Caroline and I considered that our lives had moved forward as a result of our relationship through the study, as discussed in Chapters 7 and 8.

My obligations to the co-researchers and participants derived firstly from a moral responsibility to check the powerful professional, "expert" discourses that I represented. Recognising those powerful professional discourses, I sought to resist them and use my privileged position to try and make a difference in the lives of those excluded and marginalised. The writing up of our study and the narratives inherent in it is a heavy responsibility for me, and I have tried to present the co-researchers' and participants' narratives as intact and true to them.

Ethical issues in research

Research is viewed as a scientific human endeavour that is organised according to a range of protocols, methods, guidelines and legislation (Gerrish & Lacey, 2010). Research ethics is that domain of enquiry that identifies ethical challenges with a view to developing guidelines that safeguard against any harm and protect the rights of human subjects in research (Rogers, 2008). Personal descriptions of the lived experiences of people with learning disability are a sensitive and private matter, and as such I had an ethical responsibility to adhere to key ethical principles such as respect, informed consent, beneficence, non-maleficence, veracity and justice. Our study involved more than one interaction with the participants, and therefore informed consent was more appropriately viewed as a process rather than a one-time initial event.

The strategy of “on-going consent” offered opportunities for making better-informed choices regarding participation (Knox et al., 2000). The participants were assured of their privacy throughout and after the conclusion of the project. All identifying information remained confidential to the co-researchers, my supervisors and transcriber. All participants remained anonymous, with pseudonyms used where appropriate. Informed consent is the cornerstone of ethical research (Cassell & Young, 2002). An important aspect of this is the quality of information provided to potential subjects. In relation to young people with learning disability, information had to be in a form that was accessible. Having Andrew and Caroline involved in the design of all consent forms greatly aided this process, as did the use of multiple forms of communication – spoken, photo, symbol and graphical (see Appendixes A, A1, F, G & H). Data were locked away in a filing cabinet at the university. Recognising that subjects may have never been part of research before, we incorporated a process of ongoing consent or process consent (Dalton & McVilly 2004) which meant that at every phase of the focus group sessions the subject’s involvement was constantly being renegotiated. The subjects were free to withdraw from the study at any point.

The ethical principle of non-maleficence implies that no harm should come to participants (Cormack 2000). I was mindful that the focus groups could bring up painful and negative memories. I was alert to constantly assessing levels of stress, offering subjects debriefing sessions or recourse to specific counselling should this be needed. The right to confidentiality

is essential in research (Polit & Beck, 2010) but may be conflicting. This is due to the fact that sessions may lead to potential disclosure of abuse or similar circumstances may lead the researcher to break confidentiality. However, I was always conscious to protect the respondents' identities and responses from the public domain. Identities of subjects have been concealed through the assignment of pseudonyms in data analysis and throughout discussion in the study. Participants were also advised that when their interview was recorded, transcripts would be anonymous and copies of transcriptions returned to them if requested. In relation to ensuring that respondents are shown fair treatment and justice, each individual was treated equally without judgement or prejudice.

The principle of veracity or truth-telling (Cormack, 2000) is inherently important, and I showed this by telling the participants the aim of the research and proposed outcomes. In this way, I tried to maximise the benefits that this study will bring to people with learning disability and the learning disability community.

The use of Andrew's and Caroline's research diaries as a source of data was an important tool for generating findings regarding the relational dimension. However, ethically, I had to ensure that using their personal accounts and reflections in my thesis did not compromise their right to privacy or in any way potentially harm them. As co-researchers, they actively sought recognition of their narratives. At meetings after the study ended, we discussed the use of excerpts from their diaries. Rather than anonymity, they wanted their personal accounts used in the thesis as a way of acknowledging their direct contribution. Andrew and Caroline were well aware that using these diary excerpts was a vehicle for supporting not only their voice but also a better understanding of their peers and their narratives.

My position as co-researcher

As described earlier in this chapter on my epistemological and methodological positioning, this was not a study where the researcher remained detached and an "outsider." This research was founded on a belief that issues of power and "expert" knowledge have potentially exclusionary outcomes and as such require challenging. This profoundly impacted the whole research approach. The PAR approach adopted for our study enacted critical analyses and exhibited emancipatory ideals in seeking to equalise power relationships and so-called

“expert” regimes of truth. I used the lens of reciprocity (Harrison et al., 2001) and a feminist ethic of care (Noddings, 1995) to ensure trustworthiness in the research process, from the research aims and questions to co-authorship and presentation of findings. Both the co-researchers and the participants, through a sharing of our emotional selves in and beyond the research process (described as the personal and the professional), entered a reciprocal space where emancipatory ideals became action. This emancipatory action sought an inclusive life for Andrew and Caroline and for others with learning disability, which they considered good even if not what “expert” regimes of truth considered “ordinary.”

The values I brought to our study were those of a practitioner researcher, founded on creating learning environments that acknowledged the unequal power relations between teacher and student and seeking to minimise them through a moral and ethical endeavour to value, care and reciprocate with the students towards better understanding.

Self as self

As a white, European, middle class, heterosexual male, I represent centuries of persecution, domination and control of peoples and marginalised groups across the world. The default position for selves such as me has historically been to construct superior, stable, distancing and safe selves. This was not a particularly good starting point for a participatory research study that sought to expose exclusionary policies and practices within education as a mechanism for transformation of and democracy in education. One might legitimately ask what I have to say in defence of being implicated in such a history. I always had a yearning to support those at the margins of the education system. However, let me be clear that I consider my ethical self a long way from achieving any form of comforting image of self and do not believe I ever will. All I can do is constantly strive and challenge the images of self I have inside on the journey that is life.

Self as practitioner researcher

My embodied reaction inevitably impacted the nature of the collaboration with the co-researchers and participants. What I had to attempt was to be honest to the point that I laid

bare my human weaknesses in mind and body and did my utmost to positively influence my embodied interactions with Andrew, Caroline and the participants through the research journey. What kind of relationship was I going to enter into with the “others,” Andrew and Caroline and the research participants? This was fundamentally concerned with the self I desired to be, which then naturally flows into the form of self-other construction that eventuates (Heshusius, 1994).

Heshusius described the requirement to be seperative, an agential construct, as a threat to our desired images of the self, a compelling process that is challenged through a participatory mode of consciousness. In order to challenge this exclusionary feeling, trust must drive this process, not fear. I believe this comes through taking risks in reciprocity, being open, aware and receptive in the relational dimension. Fear is natural, fear is expected, and it is how you attend to fear that will decide whether you enter the relational dimension. In what I have called the relational dimension, the unique differences of each and every individual are recognised, acknowledged, celebrated and promoted. However, the relational dimension acknowledges the inevitability of dilemma. Dilemmas are a product of the complex, transient nature of the society we live in today, where multiple realities and more than one ideal world exists (Van Hove et al., 2012).

Ethical approval

The process for ethical approval highlighted the challenges when engaging in this form of participatory research. As a newly enrolled PhD student at the University of Canterbury I was required to seek approval from the College of Education Ethics Committee for the study. I also applied to the Health Research Council (HRC) as a way of testing their perhaps more medical model-orientated guidelines to see how they would respond to this form of research with Andrew and Caroline named on the application as co-investigators. My supervisor and I attended the ethics committee hearing, me with some trepidation, but I was delighted with their overwhelmingly positive endorsement of the study and its methodology. They fully took on the research team approach with Andrew and Caroline as co-researchers and asked some searching questions. The members’ appreciation of this form of research in suggesting that Andrew and Caroline be paid was particularly pleasing. Andrew and Caroline were away on their Upp Club Down syndrome annual camp; otherwise they would have also attended. In

hindsight, I wished they had been present, because they would have been able to articulate their personal views of our aims for the research better than I could on their behalf. The study was given ethical approval by the HRC Upper South A Ethics Committee on November 18, 2008. The College of Education Ethics Committee approved the study on December 4, 2008.

The limitations of our study

This is a small-scale study focusing on the perspectives and lived experiences of a particular group of young people with learning disability. The small number of participants provided for an in-depth exploration of these young people's experiences. The student participants came from special and secondary schools, while the young adult participants had left school but had also attended both special and secondary schools. Involving young people with learning disability as co-researchers in the research team allowed for rich data collection and analysis, as well as ongoing member checking and presentation of findings through the research process. My role as an experienced teacher and practitioner researcher, and my experiences as manager of the LSTS, provided for a richer and deeper relationship with all research participants, allowing us to consider the wider implications of what the young people were communicating regarding their search for a good life. However, because of the small number of participants, the study should only be viewed as a window into the social construction of learning disability. The views of the participants are not easily generalisable as all schools have different cultures, structures and policies, as do all social institutions. Our study does not speak for or represent the voices of other young people with disability

Data presentation

The data will be presented in the following three chapters to address the overall aim of our research, that being to explore and understand what a good life means for young people with learning disability as they transition from school. Chapter 5 presents findings regarding what the young people with learning disability want and contrasts it with what they got. This leads into an exploration of the exclusionary landscape in Chapter 6, including attempts to understand the reasons for this situation. Chapter 7 describes the story of the research team and explains how attending to human values, reciprocity and interdependence allows for

opportunities and contexts in which young people with learning disability can be positioned as capable, responsible and purposeful.

CHAPTER 5: THE SEARCH FOR A GOOD LIFE

In this, the first of three findings chapters, I present the views of the students and young people with learning disability and what they considered important in their lives now and the future. The overwhelming optimism for the kind of life they wanted came through clearly from the findings. There was a good deal of excitement generated by the participants across the focus groups and they enjoyed the opportunity to meet more than once, gelling well as a group. Listening to the students three times and the young adults twice over an extended period allowed for greater insight into their lived experiences. It also encouraged them to relax and more easily communicate and express themselves. Importantly, the passage of time allowed for greater reflection. These were young people eager to tell their stories and provide their lived experiences. They wanted the opportunity to make a valued contribution in their lives and the lives of others. In keeping with the participatory and exploratory methodology adopted, I draw from the literature in relation to the findings. This allows me to build my argument through this thesis.

In exploring how these students can make the transition from school to a good life, their voice is crucial to gain deeper understanding. The chapter is in two parts: What the young people want” and: What the young people got.” I draw from both the students’ and young adults’ comments to make comparisons, acknowledge the similar goals and aspirations they held for their lives, and demonstrate that on the findings they are likely to be unrealised. I often draw on relevant literature as the findings are presented, as a deliberate strategy for locating the research within the field and providing clarity.

WHAT THE YOUNG PEOPLE WANT

The findings in this chapter suggest that the students and young adult participants held similar goals and aspirations for their life. This was despite some of the young people having left school up to five years ago. The participants identified many experiences important to them as they made the transition from secondary education on their journey towards a good life. These are presented in four broad themes that take a holistic view of the transition process:

- Further education and training in a tertiary environment

- Work experience and paid employment
- Living and relationships
- In the community

In Part 1 of the chapter, I discuss findings related to each theme.

Further education and training in a tertiary environment

A minority of student participants (5) had undertaken short tertiary courses (30 hours) over the period of the focus groups, while enrolled at school. A small number of young adults were enrolled in a tertiary course at the time of the focus groups (1) or had experienced a course since leaving school (3). However, a significant majority of both the student (9) and young adult participants (11) considered post-secondary education to be an important goal for them. Many expressed a clear desire to undertake further education and training in a tertiary environment. The word “polytech” (polytechnic) was most often referred to by the participants as the venue where they saw further education would take place. This reflected the limited tertiary options available in Christchurch to students and young people with learning disability. The word “university” was not mentioned at all in regard to tertiary study. This supports the findings of a study by O’Connor, Kubiak, Espiner and O’Brien (2012), who found that young people with learning disability rarely considered university as a post-school pathway. However, O’Connor et al. found there were many potential benefits for all people involved in university life including students with and without learning disability and university staff, for example attitudinal and greater understanding. O’Connor et al. found the most common assumption to be that students with learning disability are unable to meet the academic requirements for university admission (Eisenman & Mancini, 2010; Hart, Grigal, & Weir, 2010).

Many of the young adult participants retained a desire to experience tertiary education even though they had, in some cases, left secondary education several years before. Although both students and young adult participants expressed the desire to attend tertiary education, only a small minority of young adults had managed to realise this goal. The below findings are related to the three students who had accessed short courses while still at school.

Tertiary study while at school

A small number of student participants (4) were accessing polytech for a discrete short course while they were still enrolled at school, which provided them with insight into this tertiary environment. The Secondary Tertiary Alignment Resource (STAR) funding from the Ministry of Education to schools was generally used by schools to fund this course. The student participant's comment below was a common one and expressed her enjoyment of a short course titled "Independence Skills" targeted for people with learning disability.

Student participant: *Yes I go polytech on Fridays [pause] I like it its fun and cool there.*

The course was designed to enhance independence skills and for the young person to gain in confidence. Another student commented on how attending polytech made her feel "grown-up" and more like an "adult."

Student participant: *Yes I feel grown-up at polytech. I can be more adult like yes.*

Another student had been enrolled on a part-time module connected to the only full-time course available to students with learning disability, "Workskills." She commented on how going to the cafe helped her be "like everybody else."

Student participant: *I do Workskills course part-time I like going to the cafe [pause] like everybody else.*

The course referred to above was a module from the discrete two year full-time Workskills course that was specifically designed for young people with learning disability at the local polytechnic to gain skills for successful employment. Students could access some modules while still at school and gain credits towards certification. The student participant's comment that she wanted to go to the cafe like "everybody else" shows her willingness to be seen in the 'everyday places'.

Tertiary study post school

Both the students and young adult participants consistently described tertiary study post school as desirable and something they aspired to. Many of the student participants wanted to

attend polytech after school, and it was also mentioned by many of the young adult participants who hadn't yet been able to. Participants thought going to polytech would help them continue with their learning.

Student participant: *I want to go polytech so I keep learning.*

Student participant: *Go to polytech, yes because it help me learn.*

Young adult participant: *If I went I could find out about stuff yes.*

There are a small number of tertiary providers in Christchurch, including private and state-run polytechnics, two universities, and medical school attached to a hospital. However, there are very few courses that the participants in this study can access and, importantly, that they are provided with the right support to do so. As perhaps could be expected, student participants who mentioned the local polytech were generally those who had attended and undertaken short courses while at school.

Student participant: *Same as [name] I go to polytech because I done some of the work skills course this year.*

This is an important point in that it is difficult to make informed decisions about the future without having some experience to draw insight from. This provides a compelling argument for a more inclusive approach to tertiary study opportunities. In New Zealand, very few students with learning disability go from school into full-time courses in a tertiary setting (Mirfin-Veitch, 2003; Gladstone & Thomas, 2009; Grant, 2008; Cleland & Smith, 2010).

One student's comment made the assumption that she would go to polytech, and her response looked beyond this time to when she would get a job, providing an insight into her thought process and willingness to plan.

Student participant: *After school I go to polytech [pause] 2 years you know [pause] I'll get a job then.*

This student was making plans and plotting the stages involved in going on to complete the two-year Workskills course that would lead to a "job." She was clear about the pathway she wanted.

Some participants perceived that gaining credits for their learning leading to qualifications had value. This demonstrated that students with learning disability were drawn into the credentialised market environment impacting the education system. The unit standards referred to were supported learning unit standards recognised within the New Zealand Qualifications Authority (NZQA) framework. One student participant had gained two credits from her short course.

Student participant: ... *computer course on Fridays [pause] got 2 credits you know.*

Young adult participant: *I'm doing unit standards at college [pause] I've got heaps of credits.*

The second comment above was from a young adult participant who had done all the courses available to her, including the two-year Workskills course, and was proud of the number of credits she had amassed. My knowledge of her was that she had even repeated courses in the pursuit of credits. Her experience raises an important issue concerning the currency and relevance of courses for people with learning disability and the repetitive, “carousel effect” of tertiary study where they are placed on discrete courses that do not provide a pathway (Wright, 2005). The Workskills course is currently the only available extended full-time course of study for young people with learning disability in Christchurch. The course’s goal is to prepare its students for employment; it is an NZQA level 1 course and can lead to the National Certificate in Work and Community Skills (Supported Learning). There are 12 places, and it is oversubscribed each year.

Student participant: *I'll never get there (polytech) [pause] want to though [pause] it will help me with a job.*

The student participant’s comments acknowledge the limited opportunities, even though she believed polytech would help her to get “a job.” The student pinned her seemingly forlorn hopes on not only getting into the course but that it will also find her employment.

Some of the young adults had attended the two-year Workskills course at polytech that many of the students had aspired to.

Young adult: *I did the work skills course for two years yes.*

One young adult who was enrolled on the two-year course at the time of the focus groups articulated a clear expectation that it would lead to a job:

Young adult: *Yes, I'm gonna get a job after polytech they said so.*

This is significant because the comments from another young adult who had completed the Workskills course provided an insight into whether her ambition for a “job” would be realised in the years after completion.

Young adult: *I got a national certificate at polytech get me a job sometime [pause] maybe ...?*

The young adult's uncertain expectation that it would get her a “*job sometime maybe*” implied that she did not have a job in the period since completing her studies. When following up on this point, we found that she had completed the course over two years previously and had not found any employment, despite being registered with a supported employment agency. After an extended period at home, she had started attending a vocational service day centre three days a week.

Three of the young adults had attended the two-year, full-time discrete Workskills course directly after school, graduating in different years. Those young adults were very positive about the course and comments reflected this. Comments reflected the value of learning in a tertiary environment in terms of social capital, as a way of meeting different people and perhaps increasing social networks.

Student participant: *Yes I met loads of people there [polytech].*

Young adult participant: *The tutors were nice and the students and lots of people there you know.*

Young adult: participant *I loved polytech my friends are there.*

Young adult participant: *Yes we'd go cafe for morning tea.*

This aligns with research by O'Brien, O'Keefe, Kenny, Fitzgerald and Curtis (2008), who described the social benefits that can be derived from tertiary education for students with learning disability in a study based on a programme designed at Trinity College, Dublin in Ireland. The opportunity to develop friendships through the course is an important one for any person undertaking such an endeavour, and this was reflected in the comments above.

Summary

The findings demonstrate that most student and young adult participants aspired to and were positive about the value of tertiary study, and this was reflected in the focus group discussions. They saw the value in continued learning to help them secure employment. This aligns with a study by Migliore, Butterworth and Hart (2009), who found a correlation between participation in tertiary education and positive employment outcomes for students with learning disability. It also aligns with the current drive in New Zealand education policy and the link between tertiary education and enhanced employment opportunities. In addition to enhanced employment opportunities, the participants in our study also saw it as increasing their social networks and an opportunity to make new friends and go out socially. Enhanced social networks for students with learning disability were also found in a study by Carter, Cushing and Kennedy (2009). In our study, there was awareness by the young people of the perceived value in gaining credits towards qualifications. Young people with learning disability were aware of the credentialisation of education, raising the question as to whether they have the opportunity to benefit from any qualifications they may acquire.

However, the findings and my professional experience suggest there are very limited tertiary opportunities generally for young people with learning disability. Courses are discrete, with some evidence of course repetition, along with a real sense that any tertiary education for these young people did not provide a pathway on to the next stage in their lives, particularly paid employment. Employment outcome figures for the long standing Workskills course do not exist, but anecdotal evidence would suggest that it very rarely leads to paid employment, its stated aim. In the next section, I report on the findings related to work experience and employment for the participants.

Work experience and paid employment

Work experience

Most student participants talked about undertaking work experience while at school and commented on it in response to questions regarding what they had done to get ready for leaving school. These comments reflect work experience done at home and school.

Student participant: *I do work experience helping staff at [name] help look after the old people.*

The student participant above was working at an elderly care facility one morning a week from school.

Student participant: *I work at Mitre 10 on Tuesdays.*

Mitre 10 is a chain of hardware stores and the school that this student attended had created a link with a local store as a venue for work experience.

Student participants' comments also described a willingness to work outside of the school day, such as doing chores for mum at home and cleaning the stables out. This introduction to the world of work is an important step for any young person and is equally important for students with learning disability. It shows an understanding of taking responsibility and contributing at home through taking on chores and jobs while still at school. This could be viewed a typical situation for any young adult.

Student participant: *I do jobs at home for mum and get paid yes ... I go to the dairy.*

The student's comments above show he makes the connection between getting paid for work and spending money at the dairy. The next comment, below, acknowledges that work can be hard:

Student participant: *Every day I clean the stables out after school you know it's hard.*

Student comments also reflected an understanding that participating in work experiences while at school might help them make decisions about what to do after school, as with the student's comments below:

Student participant: *I done lots of work experience with animals I could do that for a job when I leave.*

Paid employment

The importance of work for the young people with learning disability was a recurring theme from the analysis of data across all focus groups and reflects findings elsewhere (Emerson, Malam, Davies, & Spencer, 2005). Student participants' comments consistently referred to work as being a goal. This goal did not appear to diminish for the young adult participants. This shows the high status they gave to work in their journey towards a good life. Findings suggest that the student and young adult participants saw work as providing some purpose; an opportunity to increase their social networks; and the money to be able to do things and begin to take some responsibility for their lives.

Nearly all participants either mentioned a type of job – “gardener,” “car mechanic” – or used related phrases: “job,” “get a job,” “I want a job when leave school,” “work with old people,” “work in a music shop,” “work in Burger King.” Comments reflected work as an important goal post school for the students, and this continued to be so for the young adults in the years after they had left:

Student participant: *Working hard to get everything I can out of school, getting a job, getting a flat that sort of thing.*

Young adult: *Yes I'd like a job yes to give me money to do stuff.*

Student participant: *I like [pause] if I can [pause], full time job would be good.*

Student participant: *A job is important [pause] money is important [pause] I can buy things.*

Some participants' comments showed that work provided a purpose and structure in their lives – as highlighted by Johnson and Walmsley with Wolfe (2010, p. 100) – as in the example below:

Young adult participant: *Work will give me something to do and I will have to get up in the morning then that's good.*

One might reason from the young adult's comment above that he was looking for some shape and purpose in his life. This was a man who was at home most of the week with little purposeful activity and attending a vocational day service for two days.

Participants' responses with regard to the type of work were generally realistic and reasoned.

Student participant: *I would like to work with animals and have something that is decent for me for people with disability like myself.*

Young adult participant: signed “work” and “McDonald's.”

Student participant: *Work with old people, talking to them and helping them.*

Young adult participant: *Yes work in Burger King I can [pause] cooking burgers and that.*

It was evident that the student participants who were most realistic in their responses concerning work were generally those who had undertaken work experience placements. Significantly, there were relatively few responses from the student participants relating to jobs that might be interpreted as unrealistic. Jobs mentioned that might be in this category were “train driver” and “racing car driver.” In the case of the student participant who mentioned wanting to be a racing driver, he was a young man who was a keen racing enthusiast and spent large amounts of time outside of school with his neighbour who owned and raced a stock car. He helped with basic car maintenance like checking levels, grooming and changing tyres. He went on to do a week's basic car maintenance course at a local Ford dealer. The young man who said “train driver” was passionate about trains. He had previously done a work experience placement at a heritage park with a train enthusiast's club. These examples suggest that is important to be creative or “think outside of the box” to

interpret young people's aspirations and goals concerning work, so that a practical, viable solution is found where interests can be realised.

Participants saw getting a job as a time-related process. Comments acknowledged that getting a job was not going to happen overnight and was part of a long process – requiring in some cases further education, training and support – and was about looking into the future.

Student participant: *After polytech I am thinking of getting a full-time job.*

Student participant: *Yes, I know what I want to be, but I just got to take a step at a time. I can just look after myself and build up my confidence when I go to work.*

These comments reflected the views of students who had a careful, reasoned approach to life and showed an understanding about some of the complexities and challenges involved in making future life choices.

Being paid to work was considered important and was acknowledged by most participants as a way of providing them with the money to do the sort of things they wanted in life. The comments below demonstrate a clear expectation that when you work you should get paid.

Young adult participant: *You should get a real job with real pay that's what they say you know.*

This young adult's comment reflected the People First self-advocacy organisation slogan and its political message within the local learning disability landscape. There was a clear message from other participants that being paid for work was a right:

Student participant: *I do leaflets for money ... I wouldn't do it else would I.*

Student participant: *Getting a job and living in a flat and paying rent.*

Young adult participant: *Yes I want a job that pays good money heaps of it.*

The desire for work in order to contribute to the family household, as with the young adult participant's comment, below demonstrates responsibility and some understanding of the value of paid work and what it might be used for.

Young adult participant: *If I had work it give me money and I can pay mum rent.*

Equally, it might be interpreted as an unanswered plea for work so that she can contribute to the family expenses or an expectation from other family members that she would if she ever did obtain work.

Importantly, student participants' comments indicated that some jobs had greater value and status than others, and they were able to articulate why, as with the passage below from the second student focus group:

Student participant (Stephen): *A job [pause] paid lots not mucking around with trolleys.*

Student participant (Mary): *Not pushing trolleys because that is one of the worst job you can get.*

Interviewer (Colin): *Why do you think that?*

Student participant (Stephen): *You get paid less [pause] I want [pause] a decent job for me.*

Student participant (Mary): *Yes it's lonely.*

These student participants' comments articulate an understanding that jobs have a different status and value. Stephen had undertaken work experience as a supermarket trolley attendant over one term through a supported employment agency and his views were derived from experience. Two important points emerge from this passage. There are often stereotypical roles in work for people with learning disability and in my experience being a supermarket trolley attendant is certainly one. The students' comments describing the role of a trolley attendant as poorly paid and lonely raise important issues about the types of employment people with learning disability are given, with jobs often assigned according to presumptions made by the supported employment agency staff rather than the genuine desires of people with learning disability.

Not only is the opportunity for paid work at a minimum rate important, but it should also provide other things in a person's life. Following on from this, work was seen as a way of

increasing social networks and an opportunity to meet new people and make friends, as found in research by Forrester-Jones, Jones, Heason and Di'Terlizzi (2004).

Young adult participant: *I might get some friends if I had a job.*

Student participant: *At work I can get to know people sort of thing and be with them.*

Of the two young adult participants who were in part-time paid employment, one was working 10 hours per week at a local supermarket as a trolley attendant and had been doing so for approximately three years, and the other worked at a retail outlet of a large chain of DIY stores for five hours per week. Neither was able to say how much they earned a week. However, it was clear that they derived great pride, value and a sense of purpose from the paid employment they undertook.

Young adult participant: *Yes I love my job I have to get up early but I love it I do it I do.*

Young adult participant: *I do trolleys I like it.*

Many of the participants commented on the value of money and how it was an important consideration for how they might function in the community.

Student participant: *If I don't have money I can't buy things or a top-up can I?*

They were also able to make the connection between money and being a consumer, as with the comment below:

Young adult participant: *Being paid for job give me money for CDs and stuff.*

However, there was little evidence that the students had any money earned from part-time work, apart from one student's comments that revealed they were paid to deliver leaflets. They commented a good deal on wanting to go to the shopping malls, but only "window shopped." The value and purpose of money was clearly understood, but the students did not appear to have access to money in any sense that would allow them to be active consumers.

It was evident from the findings related to work that the majority of participants viewed it as an important consideration in their lives and that they wanted to have employment at some stage. There was also a clear expectation from the findings that employment should be paid. These findings have been supported by reviews of the literature by New Zealand researchers Bray (2003) and Cleland and Smith (2010). The participants believed that paid employment would be beneficial in terms of increased social networks, a greater sense of value and purpose (well-being), financial benefits and community engagement. Some participants saw that there was a hierarchy of jobs and that some had more value and status than others, as in the dialogue concerning the supermarket trolley job. The participants aspired to a variety of employment types, but these were mostly service or manual in nature.

There was a sense from the findings that gaining employment was unlikely, in that most comments related to when the young people would get employment and not their real experiences of it. Even for those young adults who had left school four or five years previous, the comments were about employment at some future time. Nevertheless, participants demonstrated a good understanding of the typical process leading to paid employment and saw other elements as having to happen first, such as further training and tertiary study.

The expectation that young people without disability go from secondary education to tertiary or further education and training before employment has been encouraged by government policy as an expected but non-linear pathway in neoliberal times (Nairn et al., 2012). So far, the findings have begun to show this pathway is at best unusual for young people with learning disability. I now move on to present findings related to the importance of relationships in the lives of young people with learning disability and explore how they positioned these in their lives.

Living and relationships

The findings in this study demonstrated that living and being with family and friends was viewed by the young people as a very important and enduring aspect of their lives. It is clear from the literature that people with learning disability live far longer with their family of origin than people without disability (Johnson & Walmsley with Wolfe, 2010; Westcott, 2003).

The importance of family

The importance of the family to the participants was clearly and consistently communicated throughout the focus groups. They were overwhelmingly positive about the influence of their parents, siblings and other family members. It was clear that parents and family continued to provide the most support to the young people, even for those who had been away from school the longest.

Young adult participant: signed “*mum*” and “*sister*” when responding to the question, “What is important in your life?”

Student participant: pointed to symbols for “*mum*” and “*love*” from her communication book.

Young adult participant: *We all go out together on the weekend my family and me we do yes.*

Student participant: *My mum is most important.*

Student participant: *My family [pause] because they care about me.*

Many comments reflected the love and support that parents and siblings provided. The comments revealed a true and enduring commitment to their families and particularly their parents.

Young adult participant: *I love my mum she looks after me.*

Student participant: *[Sister's name] is great she always looking out for me we share a bedroom you know yes.*

Young adult participant: *My family is always there for me.*

Parents were viewed as providing a structure in the students’ lives, as in the comment below:

Student participant: *Parents are important [pause] they set rules and boundaries.*

The mother was mentioned significantly more often than the father or stepfather. Mothers were seen as providing emotional support as in someone to confide in:

Young adult participant: *My mum she's great I can talk to her about things and like she helps me with things.*

Fathers were often portrayed in the participants' comments in what might be interpreted as more of a traditional father and male role:

Young adult participant: *Dad takes me to watch Crusaders [local rugby team] they're the best we've been going there for years they're the greatest and my dad.*

Participants were able to articulate what their parents meant to them and why through their comments.

Young adult participant: *My mum and dad are the best 'cause of the things they do for me [pause] like cook for me and take me to club and out.*

Young adult participant: *You know [pause] mum does everything for me.*

The comments above also highlight a tension inherent in the relationship between parents and young people with learning disability. For parents, the desire to protect their loved one from a perceived unwelcoming community is set against a desire to let go as their son or daughter reaches adulthood (Dee, 2006).

Living away from the family home

12 out of the 14 student participants were still living with the family of origin. The one student not with family of origin was in a residential care setting. One young adult had left the family home aged eight due to a family break-up and lived in a residential services house. The other young adult had left the family home since school, moving into a flatting situation managed by a national disability service provider.

Some young people were very clear about how they saw the future and moving away from the family home.

Student participant: *Yes I want to move into a flat with friends, have my own room, a cell phone and stuff, live my life, told mum when time to go I will go.*

The student participant's comments above demonstrate a considered, reasoned plan looking towards her future. Arguably, they also present the views of a young woman who, like any other, is reaching young adulthood and expresses a desire to "*live my life.*"

There was a clear desire by most participants to move away from the family home or home of origin at some point. Some appeared more urgent to do so than others.

Young adult participant: *Yes I'm ready to go now.*

This is a common pathway in Western societies as young people without disability achieve adult status. However, in New Zealand and most Western societies, this has become more complex in recent years than the linear pathway young people from previous generations experienced (Nairn et al., 2012). It was evident from the findings that the participants had a clear expectation to move away from the family home at some point in their lives. This was not necessarily concerned with a wish to distance themselves emotionally from family but instead was related to any young people's desire to explore and find friendships, take more responsibility for their lives and make an active contribution to the wider community. Comments reflect that it was an expected transition in their lives.

The young adults who were still living in the family home were clearly expecting to move out at some stage in the future and expressed that desire.

Young adult participant: *Yes go flatting and have friends in supported living I can have my own room and stuff like.*

Young adult participant: *When I'm living independently I can do what I want.*

Young adult participant: *... I want to leave home have friends, and be independent like.*

However, the language used in the comments above suggests an underdeveloped appreciation of what living independently entails. The comments implied that once you go flatting, friends will materialise, and you will suddenly become "*independent.*" Much of the language reflected their position as consumers of special education and social welfare services. This is seen in the use of the words "*be independent,*" "*living independently,*" "*flatting*" and "*supported living.*"

There was some evidence from the findings that reflected a change in participants' views from one focus group to another, as perhaps their experiences over time informed their understanding. In the first focus group, a student was very firm in her affirmative response to the question, "Will you always live at home?" In the third focus group, she talked about a desire to move away from her parents, as the comments below reveal.

Student participant (Susan): *When you asked me first you said do I still live at home and I do [pause] now I tell mum that I want to leave home when I am ready.*

Interviewer (Colin): *So you talk to Mum about it?*

Student participant (Susan): *Yes, I will go when I am ready.*

This student participant is reflecting on her future, taking ownership and wanting to make decisions.

Findings also showed the natural apprehension for any young person making the transition from the family of origin to living away from it. The desire to maintain close links with family is clear, as Susan explains below.

Interviewer (Colin): *Will you always live with your mum?*

Student participant (Susan): *I am not really sure cos I don't want to be too far away from my mum.*

Interviewer (Colin): *Okay.*

Student participant (Susan): *I need to find somewhere near my mum and [partner's name].*

The importance of being close to her mother comes over very clearly in Susan's comments.

Other findings reflected the commonly cited tension between a parent's desire to protect their son or daughter and the young person wanting to move away from the family home.

Student participant (Amy): *Mum she doesn't want me to go.*

Interviewer (Colin): *Why?*

Student participant (Amy): *Mum thinks I'm not ready [pause] but I am [pause] well think so.*

However, there was still an element of doubt in the student participant's response – “*well think so*” – underlining the difficult transition phase that any young person must negotiate. What is important is that the young people in our study want to try.

The two young adult participants who were living away from the family home had positive comments to make regarding their situation.

Young adult participant: *... I don't live with my parents anymore I live in a flat now, I have my own room and I do lots of stuff.*

Young adult participant: *Yes [name] and me we cook for ourselves with help you know with [support worker name].*

The role of family, as one would expect, featured very strongly in the minds of the young people, and their comments reflected the enduring importance of parents and other family members in their lives. The frank and open comments by the young people allowed for insight into the nature of the relationships between parents and young people, as well as other family members to a more limited extent. Findings indicated that although the significant majority of participants were living with the family of origin, they had begun thinking about a time in the future when they would move away. This was founded on a desire to take more responsibility for their lives.

The importance of friends

The participants in our study were always eager to speak and animated when discussing friends and friendships. The importance of friends to the participants was evident in the findings. Findings reflected the reciprocal, caring nature of a friend as someone you can trust and confide in, who is supportive and who makes you happy. The participants demonstrated a reasoned understanding of what friends are and why they are important. I utilise a large number of the participants' responses to illustrate my point:

Young adult participant: signed “*happy*,” “*music*” and to photos of three people from her communication book in response to questions concerning friends.

Student participant: pointed to photos of school friends and family members in her communication book when asked who her friends were.

Student participant: *Someone who cares about you and takes responsibility and cares*

Student participant: *Someone to tell secrets with.*

Student participant: *Someone you can trust.*

Student participant: *A person who look after you and you do the same ...*

Student participant: *Friends make me happy because they care about me.*

Student participant: *Friends make you happy.*

Young adult participant: *Someone you can have a good time with.*

Young adult participant: *Someone who looks up to you.*

Young adult participant: *A friend who is caring and supportive.*

Young adult participant: *Friends are nice to you.*

The participants' comments highlighted the view that having lots of friends was important:

Student participant: *Good to have lots of friends.*

Young adult participant: *I got friends.*

Friends were someone you go out socially with, as expressed in the comment below.

Young adult participant: *I went to the movies with [name] he's my friend.*

Student participants' comments described friends who were mostly friends from the school they attended or a previous school.

Student participant: *Yes, friends at school, [name] and [name], [name], [name] is my friend.*

Student participant: *Lots of friends at my old school.*

Many participants also referred to acquaintances as “friends.” Typically, these were paid support workers, volunteers, school transport drivers, local shop owners or family members and relatives.

Student participant: *[Name] at the dairy he’s my friend.*

Young adult participant: *[Name of support worker] is my friend he is.*

A picture emerged from the findings across the focus groups of restricted and limited friendships. The vast majority of friends were classmates, which is not unusual for students without disability. However, students with learning disability rarely saw their friends outside of school, which would be usual for students without disability. Although they articulated a well-developed understanding of the purpose of friendships and their importance, the participants were equally happy to assign any would-be acquaintance they came into contact with as a “friend.” They were very keen to have friendships but appeared not to have much opportunity to develop them, except with other people with learning disability or people who provided various support. Most participants claimed they had lots of friends, but the focus group findings did not support this. Friendships were within discrete groups. Rarely did comments reflect interactions with friends without disability. Not one young adult participant named someone who wasn’t a family member, a friend from school days, a member from a discrete club or a support worker.

Intimate relationships

There was relatively little comment on intimate relationships, other than “talk” concerning “boyfriends” or “girlfriends.” There were no explicit comments related to having intimate relations with someone. The comments did provide a range of views, with some considering it fine to have more than one boy or girlfriend while others saw this as not. Nevertheless, having intimate relationships was seen as an important step for most people. Many students commented that having “*someone special*” to share their lives with was important and something which they would want at some future stage in their lives. One student described this as “*someone I like but not sex you know.*” The language they used was “*boyfriend,*” “*girlfriend,*” “*wife,*” “*husband*” and “*married.*” No-one used the term “partner.” Only one male student commented on being currently in a relationship. However, from my knowledge

of the student group and discussions with many of their teachers and parents over the years, I was aware that they were always talking about each other as being in a boyfriend or girlfriend relationship. Opportunities for intimacy among the young people appeared limited.

Student participant: *I hardly see my girlfriend, it's difficult you know [pause] her mum and stuff, I can't get around much, I got a bus pass though.*

The student participant comments hint at greater issues concerning how young people with learning disability can develop effective friendships and intimate relationships in an environment where they are usually under the surveillance of others, whether family or support workers. This also can result in restricted personal lives. Findings referred to having a relationship at some time in the future, along with the desire to getting married.

Student participant: *Yes I want a boyfriend when I am ready.*

Young adult participant: *I get married but not now though.*

Student participant: *Yes a girlfriend I want to be with someone.*

The young people's comments reflected stereotypical responses about relationships: for example, that you should be married if you are going to have children. Most thought they would like to have children but expressed uncertainty.

Young adult participant: *You need to be married for having children.*

Student participant: *I think I would like kids you know but well it's a big step isn't it.*

The findings related to friends demonstrated that participants had a well-developed understanding of the value and purpose of having and maintaining friendships. However, there was little discussion or evidence that the participants had any meaningful friendships with young people without disability. This supports a study by Forrester-Jones, Cambridge, Carpenter et al. (2006). The vast majority of social interactions took place within the family context, supporting research by Lippold & Burns (2009), or with support workers, as in research by Robertson, Emerson, Hatton, Elliott, McIntosh, Swift et al. (2005). A strong desire for friends and the nuanced appreciation of their value by the research participants

contrasted with the lack of opportunity to develop meaningful and sustained friendships and more intimate relationships. Therefore, we should not only consider the opportunity to develop more meaningful friendships but also take account of and target which relationships would be most important for the person (Cummins & Lau, 2003) in their journey towards a good life.

In the community

The notion of community or living in the community has in many ways been defined as different for people with learning disability in comparison to people without disability (Westcott, 2003, p. 212). How young people with learning disability can engage positively with and gain a sense of belonging to the community in which they live is a key question in this thesis in relation to all people's journey towards a good life. Solutions to this can perhaps move us forward from the notions of community participation or presence found in policy and service rhetoric and reported below. Historically, community for people with learning disability has always been closely related to reliance on service systems (Metzel, 2004), and I believe is still relevant in New Zealand today.

Findings demonstrated that there was a clear desire from the participants to be present in the community. They communicated this as being seen in the everyday places doing the everyday things those without disability might do.

Student participant: *Go to maccas ... [McDonalds] I love it.*

Young adult participant: *Yes, I go to the Mall ...*

Student participant: *I go swimming at [name].*

Student participant: *Go for a coffee and take a chill pill.*

Young adult participant: *I go to Special Olympics on Fridays.*

Young adult participant: *I like going to the mall and hanging out.*

Young adult participant: *My sister took me to the cinema to see Harry Potter.*

They talked about going to the mall, swimming, fast food outlets and the cinema, participating in Special Olympics events and using the local bus service. This can be understood as presence in the community by undertaking activities in it.

Student participant: *I go to see my friends and swimming and things like that.*

Young adult participant: *I like the bus and go to the mall.*

However, comments suggested their participation in the community was almost entirely with family members, school staff and paid or voluntary support workers who supported them in the community.

Student participant: *My support worker takes me to club.*

Young adult participant: *I go with school swimming yes.*

A desire for community responsibility

Despite what might be described as peripheral participation, findings demonstrated the participants' caring nature and their recognition that being part of the community involved notions of citizenship.

Student participant: *Just being there really and helping out people in need.*

The participants had an understanding that being part of the community meant taking responsibility to contribute towards the well-being of the people in it. There was an understanding of the need to help other people in the community that they perceived as less fortunate, as with the comments below.

Student participant: *Homeless people [pause] we need to care for them, they have no homes or food or clothes [pause] we need to care for others in our community.*

It is interesting to note that the participants, as marginalised people themselves and the recipients of care and support, acknowledged there were people in need of their support and that they needed to help them as a result.

Student participant: *I picked up an elderly person's money he dropped it.*

Participants were able to articulate how they could provide that help and support, as in the student's comment above where he described picking up an elderly person's wallet. The participants communicated a sense of community responsibility, wanting to help people in their community they perceived as older or less fortunate.

Student participant: *I want to work in the gardens and keep it tidy for Christchurch.*

In this way, they wanted to be of value to the community. This sense of community responsibility for the young adult participants was heavily influenced by family and their experiences in the vocational day services that the majority attended.

Young adult participant: *I collect all the litter in my street you know.*

The young adults naturally described community through their experiences in the vocational service day centre. It was noticeable that the young adult participants found it difficult to communicate what they did during the day at the vocational day centres they attended.

Young adult participant: *I just do my thing like walk around and talk to staff.*

Young adult participant: *Yes I love going out with everyone and [name] and seeing other people.*

Findings indicate most activity at the day centre was not vocation-based or leading to enhanced skills or training. Comments gave an impression that activities were run in large groups and were mostly undertaken in the centre or close by.

Young adult participant: *We sit at a big table and do drawing with [name].*

Findings under this theme would suggest that the young people with learning disability clearly wanted to be active members of the community and expressed notions of citizenship and a willingness to help others in it. If we accept that part of gaining a sense of community belonging requires some form of reciprocal relationship between the young adults with learning disability and other people in the community, there was little evidence to support this proposition. Findings would suggest that the students with learning disability appeared

more active in the community and had a greater sense of citizenship than the young adults in our study.

Most participants undertook the sorts of activities anyone might do in the community, such as shopping, eating, exercising and attending clubs. However, all the community activities appeared to be either part of a discrete school or vocational service day centre, or undertaken with family, school or day service staff.

Johnson and Walmsley with Wolfe (2010, p. 132) have suggested that “geographical communities are in decline.” This is at a time in New Zealand where people with learning disability are expected to “do everyday things in everyday places in communities” (Enabling Good Lives Report, Office for Disability Issues, 2011, p. 2). I suggest we need to focus on relationships and not geographical notions of community in finding solutions to the continuing exclusion of young people with learning disability.

The first part of this chapter has presented the clear “voice” of the participants in relation to their goals and aspirations, the experiences they felt were important and the kind of life they wanted. Through the findings presented, there is a clear sense of the young people’s optimism for their future lives. The students and young people with learning disability clearly viewed learning in a tertiary environment as important and believed that it would help them to obtain paid employment at some stage. They also saw family and friends as continuing to play an important part in their lives in providing stability, structure and support during the often difficult transition phase. Even though the young people expressed a close and enduring bond with their parents and families, they also wanted to live away from the family home at some stage in the future. Their desire to not only be in the community but be active contributors within it was also a strong theme that came through in the findings. Friends and sustaining friendships was considered a significant factor in the lives of the participants, both in the present and in their future journeys towards a good life.

The overwhelming optimism of the students for their future lives does not appear to diminish over time, as the young adults retained many of the same goals and aspirations in the years since leaving school. However, the findings presented in the next sections will demonstrate that this optimism for their future lives presents challenges in its realisation.

WHAT THE YOUNG PEOPLE GOT

To understand whether the participants' optimism for their future lives was well placed, I now present findings that begin to expose the stark reality and an alternative narrative that acts against their optimism. The exclusionary environment described over the next sections illustrates the challenges for young people with learning disability searching for a good life. Their opportunities to take responsibility for their lives and to contribute and develop a sense of belonging to the community are limited by the kind of lives these young people are able to realise. The findings in the next sections are presented in five themes:

- Limited tertiary education opportunities and pathways
- Limited employment opportunities
- Limited social networking opportunities
- Limited living opportunities
- A limited sense of community

In addition to the focus groups findings, I also draw on my professional practice and experience as manager of the LSTS and my conversations with policymakers, educational leaders and teachers to describe the transition landscape.

Limited tertiary education opportunities and pathways

Young adult participant: *I met other people with disability at polytech it was great but it didn't get me anywhere, I want a job.*

Young adult participant: *I did Work Skills you know and now I'm at [name of vocational service].*

These two young adults' comments portray the reality for young people with learning disability in relation to tertiary study. The second young woman quoted had completed the two-year, full-time Workskills course two years previous to the focus groups and was now attending a local vocational service day centre, despite her goal being paid employment. The landscape for young people with learning disability leaving school in Christchurch is one of

limited and discrete courses with limited places that crucially do not provide a pathway onwards in their life journey. Tertiary opportunities at university, as earlier mentioned, were not an option available for people with learning disability.

Students with learning disability, the overwhelming consumers for the Workskills course, are simply moving from one specialist setting in school to another specialist setting in tertiary education, where the captive audience provides a small but steady stream of “paying customers” eager to experience a more adult environment without it actually moving the young people further on in their goals and aspirations for life. The Workskills course was designed to prepare its students for employment, but very rarely did anyone obtain paid employment on completion. Findings from this study support data from the Lead School Transition Service in Christchurch (Gladstone & Thomas, 2009) that found that large majority of young people with learning disability ended up transitioning directly into a vocational service day centre on completion of the course. Findings from our study suggest that this is not what most of the participants wanted.

Limited employment opportunities

Young adult participant: *I been trying for a job yes [pause] for years yes.*

Young adult participant: *No job for me yet.*

Young adult participant: *They keep telling me there no jobs I don't know what can I do.*

One young adult participant had left school over three years before and was attending a vocational day service. She had been signed up by a local supported employment agency since leaving school. Paid employment was her goal, and also the aspiration for the majority of students and young people in our study, which reflects the literature generally for people with learning disability (Bray, 2003; Forrester-Jones et al., 2002; Cleland et al., 2008; Johnson & Walmsley with Wolfe, 2010). However, not one young person who participated in this study was in full-time paid employment – defined by the Ministry of Social Development as work that is 30 hours or more per week – even up to five years after leaving school. The young adult participants’ comments above reinforce this picture. The two young adults who

were employed were working part-time, a few hours a week. This suggests that for those student participants who were undertaking a range of work experiences while at school, these experiences might raise expectations for gaining employment after school only for them to go unrealised. This has important implications in regard to expectations for this group of young people and whether they will realise their goals. The literature has indicated that employment increases social networks (Forrester-Jones et al., 2004) and socio-emotional well-being (Jahoda, Kemp, Riddell, & Banks, 2008). This contributes to a person's search for a good life.

Limited social networking opportunities

Student participant: *I don't really have many friends [pause] I want them though yes.*

Young adult participant: *I never mix with people where friends are.*

People with learning disability in Western countries are typically found to have limited social networks (Chappell, 1994; Hall & Hewson, 2006; Mason, Timms, Hayburn, & Watters, 2013; Reinders, 2002). The participants' comments above illustrate the lack of social networks young people with learning disability have, as found in research by Mason et al. (2013). Findings in our study indicated that family remained the most common people in the participants' lives. Although the participants were keen to interact with people without disability, there was very little evidence of the participants having friendships with young people without disability beyond the network of family, specialist school settings and vocational service staff or other support workers. Having friendships has been shown to increase integration and reduce isolation within the community (Barber & Hupp, 1993). As described earlier, most participants still lived with their parents. Living with parents has been shown to reduce social networks to networks deeply embedded with those of the mother (Krauss, Seltzer, & Goodman, 1992). The evidence in our study also suggested that the participants were more likely to be involved in activities with friends who also have learning disability, as found in research by Emerson and McVilly (2004).

Student participant: *I go Special Olympics club and [classmate's name] she comes too.*

The students and young adults mostly socialised in discrete environments, either at home, school and vocational day services or discrete clubs in the evening or weekends. The socialising took place mostly with other young people with learning disability or family. Socialising outside of these locations was heavily supported by family, volunteers or paid support workers, who accompanied the young people in activities within the community such as swimming, bowling, the cinema or a meal out.

Young adult participant: *My support worker takes me to club.*

The young adult's comment above, referring not to the person's name but their job title, reflects the "language of support" and shows the person's reliance on disability services.

There are a number of implications for the students and young adults from the findings in relation to their social networks. Research has shown that if you are largely excluded from tertiary opportunities and employment, your social networks are likely to be restricted (Jahoda et al., 2008). If the only socialising young people do is within discrete clubs like Special Olympics or the Upp Club, then this could restrict their opportunities to extend their social networks, as found in a study by Lippold and Burns (2009). The history of learning disability accounts for how families responded to fears of exclusion from the wider community by creating special groups, societies and clubs where people with learning disability could gain a sense of belonging. Such environments provided an alternative narrative to one of failure and rejection (Johnson & Walmsley with Wolfe, 2010, p. 145). However, this overreliance on family members or support workers for getting out into the community has been shown to restrict social networks (Hall & Hewson, 2006). The opportunity to interact with same-age peers without disability is restricted when the young people are out with older people such as parents, adult volunteers or support workers (Lutfiyya, 1991). Likewise, if they cannot travel independently and are reliant on family, volunteers or paid support for getting around, then their social networks are likely to be restricted (Chappell, 1994). If people with learning disability live with their families well into adulthood, or reside in a residential service long-term, then their social networks are again likely to be restricted.

Limited living opportunities

Young adult participant: *I live in [name of residential care facility] yes bit strict I'm in a flat out back now with some new people [pause] I don't know them you know.*

This young adult participant's comments highlight a number of issues confronting young people with learning disability in terms of where, how and with whom they live their lives. My experience listening to the stories of people with learning disability and their parents as manager of LSTS has given me the impression that when people with learning disability move into supported living, it is frequently with people they don't know and have little in common with, and it is often in a restrictive social and emotional environment. People with learning disability are usually expected to "fit in" to the service system rather than the other way around. Below, I utilise a discussion from a co-researcher team meeting on February 16, 2012 to illustrate the restrictive environment of a local residential service where Andrew had been living. He was in a flatting situation with another person.

Andrew: *Remember when you and Jill were coming for tea at [name] and you couldn't.*

Colin: *I think so.*

Caroline: *Yes, you know when [name] wouldn't let you.*

Andrew: *Yes, she said it would be too disruptive for everyone.*

Caroline: *That's rubbish.*

Colin: *Oh yes interesting that wasn't it.*

Andrew: *Not really I wanted you to but she tells everyone what to do all the time.*

At the time of the team meeting, Andrew had been having a good deal of trouble with the residential service provider and in particular the manager, who expected everyone to fit in with the service routine rather than encouraging people to take on some responsibility for their lives. I return to this story later in the thesis through the relational dimension to demonstrate how Andrew used great skill in dealing with the situation he found himself in.

As stated, most student and young adult participants in the study lived with their family of origin. This can be said to mirror current trends in New Zealand and other Western countries, where young people without disability are living with the family of origin much longer or else leaving then returning, often many times. This is described by Nairn et al. (2012) as part of the change from a linear transition pathway to a non-linear pathway. This change has been linked to the increasing cost of tertiary study and housing in New Zealand. The result has been that all young people are living at home longer, as found in a study by Wyn and Dwyer (2000).

Most participants in our study living with the family of origin expressed a desire to move out at some stage in the future and acknowledged that it was a long-term goal. The two participants who were not living with the family of origin were both being supported by disability services, either in a residential or a flatting situation. None of the young adult participants had moved out of the family home since leaving school. The findings in our study support the position that young people with learning disability will remain in the family home much longer than young people without disability. In addition, if they don't, they are most likely to live in a residential facility with other people with learning disability, who they didn't necessarily choose to be with.

Interestingly, one of the participants commented on his brother going away for the year travelling on his "overseas experience" (OE) and wanted to do the same. In recent history, the OE has been a rite of passage for many young New Zealanders.

Student participant: *[Brother's name] off for a year yes travelling and drinking beer with his mates, he's going where they eat pasta yes.*

The comment provides a reminder of how limited and restricted young people with learning disability's lives are when contrasting with young people without disability. I have never heard of a young person with learning disability going off on their OE.

Limited sense of community

As described earlier, the participants in our study expressed a clear desire to be active in the community by taking responsibility for and contributing to it. However, there was evidence

that the community response was generally indifferent and sometimes uncaring. Findings illustrate the participants' often negative experiences in the community. Community has often been used as a term by policymakers to describe how people with learning disability should live their lives as in "care in the community," "community inclusion" and "community participation," without really defining what they mean by it. This appeal to community is difficult to rationalise in a liquid modern society where community is being slowly deconstructed (Bauman, 2008). In the history of learning disability, community has been used as the binary opposite to institution in seeking solutions to the "problem" of learning disability through assimilation. Bauman (2001) views community as a complex and multi-layered term. Being included in the community for people with learning disability has been reliant on structural changes (Johnson & Walmsley with Wolfe, 2010, p. 135). The participants in this study had not experienced the institutionalisation or deinstitutionalisation their predecessors had and so in many ways were "present" in the community. However, "participation" in the community was mostly defined by family and the services that supported them. Thus, how young people with learning disability could find a sense of belonging in this way became an important factor in this thesis.

There was limited evidence to suggest that they got the opportunity to gain any real sense of belonging in the community through positive interactions with people without disability. As illustrated earlier, the participants were able to articulate notions of citizenship and taking responsibility for the well-being of others in their endeavour to belong. Nevertheless, the findings showed that they rarely interacted with people in the community other than family members or support workers. Although they were present in places defined by the community, such as the shopping mall, cinema or swimming pool, their participation was in many ways just "window shopping" as passive welfare consumers (Myers et al., 1998). The comment below exemplifies this.

Student participant: *Yes, I go to the mall as I see lots of people I look at them and the windows.*

This student wants to be part of the community but appears to be operating on the periphery looking in.

Bauman's metaphor of the stranger is useful in beginning to position the students in this study as operating at the margins of the mainstream community, and it is a theme I further develop through the findings and discussion chapters. This is illustrated in the comments below that reflect apprehension by a student about participating in her local youth club.

Student participant (Susan): *I don't go to like [pause] I don't do like youth club. I would sometimes normally go up the street just to have a look and then go to the library.*

Interviewer (Colin): *Why?*

Student participant (Susan): *Cos I'm different.*

Interviewer (Colin): *Why?*

Student participant (Susan): *I was born with [pause] I think it was Autism syndrome and I would find it hard to do things with other people.*

Susan comments on being "different" because she identifies as a person with Autism and believes she would find it difficult to be accepted for who she is. However, she attempts to cross that line of acceptance by walking up the street to have a look. One can imagine her making that lonely walk and standing across the street: "the stranger" watching, wanting to cross the road but not daring to step over the threshold of the youth club door for fear of being treated as "different."

The next data extract from the second student focus group describes a negative experience that a student participant had in the community when travelling on the city bus service.

Student participant (Mary): *... it was a bus driver, I was sitting down in the seat and I went to get up and there is this person saying that I stink, this isn't very nice and when I got out of the door the man shut the door on me.*

Interviewer (Colin): *Right.*

Student participant (Mary): *I was in the middle of the door on the bus.*

Teacher assistant: *Did he realise that he had shut the door?*

Student participant (Mary): *Yes, but he kept on carrying on.*

Interviewer (Colin): *That was rude.*

Student participant (Mary): *Yes he knew but he didn't say anything.*

Interviewer (Colin): *Okay, well that's not very kind is it?*

Mary was upset by the experience and was emotional when telling us the story at the focus group discussion. She clearly considered her treatment by the passenger and the bus driver to have been hurtful. The next extract describes an animated discussion generated among the student participants concerning the verbal bullying in the previous story from Mary.

Interviewer (Caroline): *What do they say? Are they nice?*

Student participant (John): *Not really.*

Interviewer (Colin): *No, okay.*

Student participant (John): *They are a bit rude.*

Interviewer (Colin): *Are they are bit rude?*

Student participant (John): *Very rude.*

Interviewer (Colin): *Are they?*

Student participant (Stephen): *Why they are like that to you?*

Student participant (John): *Rude names, very rude names.*

Student participant (Stephen): *I quite agree on that question.*

Student participant (Mary): *Yes they call me fat which I don't like.*

Student participant (Stephen): *You know that isn't true.*

Interviewer (Colin): *Peter you were going to say.*

Student participant (Peter): *Mary you just have to ignore them if they say something like that to you.*

Student participant (Stephen): *It's true.*

Four of the students were involved in this particular animated discussion, with John first describing how students without disability call him “*very rude names*” and Stephen acknowledging that it has happened to him as well. The students were very supportive of each other and offered advice on how to deal with such incidents. When Mary told of being called fat by other students, it was Peter and Stephen who provided the strategy of just ignoring them. The strength of support among the participants is revealing and shows a reciprocal and caring nature. However, it also shows the difficulties of a regular school environment, where venturing from the “safe haven” of the special unit presents challenges for students with learning disability in an exclusionary environment.

The second half of this chapter has focused on what the students and young people in this study were “allowed” to do in relation to the optimism they held for their future lives described in Part 1. It has highlighted a transition landscape from school into post-school life defined by restrictive pathways, limited opportunities, little responsibility within an exclusionary environment and a generally unwelcoming community. In comparing the student participants’ findings with those of the young adults, some conclusions can be drawn. The optimistic and positive outlook displayed by the student participants about the roles they desired post school would appear to be misplaced. The years after school were defined by little interaction with people without disability, apart from family, friends or paid staff, and some negative experiences when there was. Most young adults were attending vocational day services in the years after school, with a very small minority having experienced discrete tertiary courses and some voluntary or part-time work. The reality was that work in any shape or form was limited in the years after leaving school and paid employment rare. Any paid employment was restricted to a few hours a week and was usually temporary, lonely and low paid, as reported by participants in the case of the supermarket trolley attendant job. Tertiary education was also scarce and did not appear to provide a pathway towards the young people’s goals, particularly paid employment.

The usual pathway for the young adults on completion limited discrete tertiary opportunities or part-time employment was into a vocational services day centre, or daytimes were spent with the family of origin. This gave the distinct impression that opportunities were just delaying the inevitable move to a day centre, where most went straight from school. The participants in this study clearly wanted more than day services placement – particularly the

students with learning disability who held clear goals for their lives. If we accept that further education, training and paid employment plays a part in our journey towards a good life, as it does for young people without disability, then it is clear from the findings in this study that young people with learning disability are mostly excluded.

Chapter summary

The findings presented in this chapter show that the participants with learning disability in this study had similar goals for their lives to any young person. After leaving school, they wanted to experience tertiary education and obtain paid employment so they could enjoy the material things in life. Further, they saw family and friends as crucial and continuing parts of their future lives. The findings began to challenge taken-for-granted notions concerning learning disability in relation to presumptions of competence and reasoning. In their narratives, the young people with learning disability conveyed a reasoned outlook and a nuanced understanding of some of the important things in life, such as caring for others and what it means to be part of the community. However, their concerns did not appear to be reciprocated by some others in the community. The young people demonstrated the desire to have some purpose and value in their lives, and they saw tertiary qualifications and paid employment as a way of gaining a sense of belonging.

The second half of this chapter suggests that transition experiences for the young people with learning disability are exemplified by limited opportunities and pathways. It is clear from the findings that the students and young people with learning disability want something more.

In the second findings chapter, Chapter 6, I use the “voice” of the young people to examine inclusive and special education policy and practice. If young people with learning disability do not appear to be realising their goals in the years after school, we need to understand why in order to offer some possible solutions. Why are there restrictive pathways for the young people? I explore the exclusionary landscape for young people with learning disability and begin to examine possible reasons as to why it leads to unrealised lives. I consider how relationships at both the macro and micro level appear to influence the success or failure of the transition process for young people with learning disability.

CHAPTER 6: STRANGERS IN POLICY AND PRACTICE

All societies produce strangers; but each kind of society produces its own kind of strangers, and produces them in its own inimitable way.

Zygmunt Bauman (1997, p. 17)

In Chapter 5, I presented findings in relation to what the students and young people with learning disability *wanted to do* and their powerful insights and overwhelming optimism for the future in the search for a good life. As a comparison, I then presented findings in relation to what they were *allowed to do*. The young adult participants in the years after leaving school mostly held the same goals as the student participants still at school. However, findings indicate that the young people were unlikely to realise their goals in the post-school years. The post-school years are defined by very limited further education, training or employment, limited social networks and living at home in the family of origin for the foreseeable future. I will now explore and examine the situation that acts to position young people with learning disability at the margins of the education system and wider society. Post-school pathways appear restrictive and mostly lead directly into a vocational service day centre. I will argue the implications of this outcome results in lives unrealised as the young people make the transition within an exclusionary landscape.

In this the second findings chapter, I explore the exclusionary landscape through an examination of transition-related education policy and practice, utilising the clear “voice” of the young people with learning disability. I do so in an attempt to understand why this exclusionary landscape exists. I utilise the metaphors of Zygmunt Bauman to illustrate the position of students with learning disability in education. I will argue within the secondary education system, students with learning disability follow a separate transition pathway, in part controlled and managed by special education services within the MoE and specialist vocational services within the MSD. As a result, they are cast as “strangers” to the regular education system. I suggest that this fails to recognise the students’ capabilities, rights and responsibilities or acknowledge the positive contribution they can have on their lives and the lives of others if provided the opportunity and the right support. My argument is that

inclusive education policy and practice has failed to have any meaningful impact towards enabling these young people to realise their goals and aspirations. This acts to consign them as strangers at the margins of a school system preoccupied with the latest education initiative related to standards, performance and prescription. Throughout this chapter, I draw from the literature to position our findings.

Students with learning disability as strangers to mainstream education

Although he is not usually linked to disability studies, a significant body of Bauman's work has focused on marginalisation and exclusion from community (Hughes, 2007). Bauman's social thought emanates fundamentally from a humanistic sociological position (Tester, 2002). I draw on his sociological thought and use of metaphors to describe those people who are viewed as different (Hughes, 2002, p. 572). As described in Chapter 2, contemporary social responses to people with learning disability have required them to conform, which deny their unique difference. Bauman has been conspicuous in developing a social theory of the stranger, and his fairly recent work has contributed to this intellectual project. In his books *Work, Consumerism and the New Poor* (1998a) and *Globalisation: The Human Consequences* (1998b), Bauman has been concerned with the sociocultural processes that create the "other" in contemporary Western societies – particularly that other who has been excluded from an increasingly globalised and competitive consumer society, described in Bauman's terms as "*flawed consumers*." This has much of relevance for young people with learning disability, who, I argue, are excluded in this way.

Bauman has characterised modernity as a normalising culture, and his interest lies in how social and cultural practices create and exclude strangers (Hughes, 2002). Modernity's response to strangers was fear and a desire to exclude those who were different (Bauman, 1989a). In this way, for example, people with disability were historically institutionalised. Bauman (2011) viewed postmodernity as participating in cultural and material consumption. Whether the young people in this study are able to celebrate the "postmodern difference" and be active consumers has relevance in relation to their journey towards a good life in New Zealand society today. Chapter 5 described the young people with learning disability as wanting the same material things that most people want. However, they are not active consumers in this sense but are mostly welfare consumers, and this contributes to them being

positioned as strangers in today's society. Bauman argues that modernity is not replaced by postmodernity. In this sense, the other remains different and therefore a stranger and not valued as a result.

In these next sections, I utilise Bauman's metaphor of the stranger as a tool for exposing the exclusionary landscape for students with learning disability within New Zealand education policy and practice in relation to careers and transition. The exclusionary landscape for these young people during their transition years to post-school life is encapsulated by Bauman's metaphor of the stranger. I use it to describe students with learning disability operating in a form of parallel system as strangers to the mainstream of education. As described in Chapter 1, these students' lives remain largely determined and controlled by special education policy and by service systems and professionals (Smith & Routel, 2010). This acts to position them as strangers to the mainstream of secondary education, since they have little contact with its structures and systems or with students without disability and staff. The majority of students in this study were educated in a special school and therefore were not directly involved with the mainstream of secondary education. Those who were enrolled in a regular school were all educated in a special unit or learning support class and received their education separately from their mainstream peers. Therefore, these students are consigned to the responsibility and control of specialist staff, who are typically Special Education Needs Co-ordinators (SENCOs), special education teachers or learning support teachers, therapists, the STAR coordinator or teacher assistants. I suggest that this signals strongly to mainstream school processes and teachers that they can be absolved from any meaningful responsibility for students with learning disability. My argument being there is currently no coherent structure or, importantly, expectation in place to include students with learning disability into mainstream career and transition processes. The implications for this situation are that students with learning disability are corralled along restrictive pathways they do not want, as highlighted by the findings in Chapter 5.

Career and transition education in schools has been receiving a good deal of interest in policy work recently with the high youth unemployment rates in New Zealand (Ministry of Education, 2010). This is evidenced in the programme, Career Education Benchmarks, Vocational Pathways and the Education Review Office's (ERO) inspection work related to how well schools are preparing students generally for further education, training and

employment. It is also evidenced in the key policy work related to students with learning disability, *Success for All – Every School, Every Child*. In Part 1 of this chapter, I explore how transition-related education policy excludes the particular students with learning disability in our study, leaving them as strangers to the career and transition framework students without disability experience.

STRANGERS AT THE MACRO LEVEL

Success for All – Every School, Every Child (2010b)

Student participant (John): *I'm stuck in the unit all week with other people like me and I don't really go there [name of secondary school] you know just [name of unit].*

John's comments suggest a contrast with the policy work *Success for All – Every School, Every Child*, the Government's vision and work programme to achieve a fully inclusive education system. This programme built on the views of more than 2,000 people from across New Zealand who made submissions to the government's review of special education in 2010. The government set a target of 100% of schools demonstrating inclusive practices by 2014 and has a range of activities to achieve this. These activities are premised on improving inclusive practices and improving special education systems and support.

What does “success for all” mean for John? John's comments indicate even though he was enrolled in a unit on a mainstream school site, he had little contact with the school outside of the unit. His own realisation that he spent most of the week in the unit is revealing, as are his comments expressing that he and other people like him felt isolated. He uses the names of both the school and unit, reinforcing the distinction between the two. A student with learning disability being physically located in a mainstream school does not mean they are included (Slee, 2011). Some of the student participants had attended a mainstream secondary school and then were enrolled in a special school, including co-researchers Andrew and Caroline.

Student participant (Susan): *I don't go normal school now I go [name of a special school] ... Yes I did go to a secondary school but they said I couldn't handle it all that moving about.*

Susan comments above on why she made the move, saying that “*they said I couldn’t handle it all that moving about.*” This is a common reason provided for why students with special needs often end up in a special school despite in many cases beginning in a secondary school. The fluid, competitive, subject-orientated nature of the secondary school is often touted as a reason for excluding students with special needs from secondary schools or for educating them in separate units or learning support classes.

In supporting the vision of *Success for All – Every School, Every Child*, ERO (2010b) undertook a review of 229 mostly primary and intermediate schools: *Including Students with High Needs*. Ironically, special schools were missing from this review. The review found that only 50% of the schools demonstrated that they were mostly inclusive, based on a self-review process and a range of indicators. The review was based on students with high needs, who make up three percent of the student population and receive extra support funding. This would include all the student participants in this study. Significantly, only 34 schools reviewed were secondary. There is often an assumption made by teachers that it is more difficult to include a student with high needs in the secondary school environment than in primary school, and this may have influenced ERO’s decision to review mostly primary and intermediate schools. This was acknowledged by ERO in the below comment from their report:

The issue of mainstreaming is complicated for some students with high needs when they get to secondary schools. Some secondary schools have special education units where students with high needs learn for at least some part of the day. The students in these units may be included in a mainstream form class as well as the school-wide social, cultural and sporting activities, while also spending a majority (or even all) of their learning time in the special education unit. (p. 10)

ERO here acknowledged that students with high needs can spend all their time in the unit. The four students with learning disability from the study who were enrolled in a mainstream secondary school were all either in a special unit (3) or learning support class (1).

Student participant: *I don’t really talk students outside the unit, no friends, I don’t think they like me.*

This student's comment on not really talking with students outside of the unit illustrates her separation from the mainstream school environment. The fact she feels she has no friends and other students do not like her reinforces a sense of the unit's isolation from the rest of the school and supports the verbal abuse commented on in Chapter 5 by some student participants.

Furthermore, the ERO report stated that teachers in secondary schools believed students with high needs were best educated in a special unit.

The decision made by the staff at these schools is that many special education students are better served in the special education unit, especially when it comes to learning the core subjects and skills (numeracy, literacy, science and so on). This judgement has often been made because the teachers in mainstream classes were not well prepared to meet the diverse needs of a classroom that includes a student operating at level 1 or 2 of the curriculum. (p. 10)

My professional knowledge of the special units and learning support classes in Christchurch and elsewhere corroborate the findings in our study that students with learning disability spend very little time away from these specialist facilities on the mainstream school site. When they do venture away, it is generally for social, cultural and sporting gatherings, but these are almost always with students and staff from other special units or special schools. In addition to the special education staff from the unit and learning support classes, the only other staff who would generally have any contact with the students with learning disability were other specialist staff such as SENCO, therapists and the STAR coordinator.

Comparing data from a self-review process risks widely differing interpretations by individual schools, and ERO found this to be the situation. The report cited the difficulties schools had even in identifying who their students with high needs were and indicates the lack of a structure in schools to track and include these students effectively.

The key question that emerges from this review is: how can more schools become better at including students with high needs? Schools invest in various professional development courses that provide specialist knowledge to teachers and support staff. Similarly much of the professional support available from Group Special Education (GSE) and Resource Teachers: Learning and Behaviour (RTLb) is aimed at supporting the inclusion of individual students. More can be

done to use school-wide professional learning and development processes to make schools more inclusive. (p. 1)

ERO's comments are revealing and concur with my professional experience that specialist education and therapy professionals provide programmes for individual students in isolation that do little to resolve the systemic issues about how to encourage a whole-school community to be more inclusive. Whole-staff professional development is an important element in developing whole-school responsibility for all students. The leadership of schools through their school systems, particularly their career and transition planning processes, need to acknowledge this and ensure that students with learning disability are included in whole-school planning. A further example of this isolation from the mainstream school systems came later in ERO's report where it highlighted that only 15% of the schools reported to their Boards of Trustees regarding achievement for students with high needs. In my professional conversations with teachers in the LSTS schools, it was clear they did not think of achievement for students with learning disability in the same way as students without disability, perhaps explaining why so few schools reported on it. Achievement for students with learning disability is still framed in a discourse of specialist interventions, adaptive curricula and assessment processes, and pseudo-vocational pathways.

ERO conducted follow-up review reports in April and September 2012: *Including Students with High Needs: School Questionnaire Responses (1 & 2)*. These reports and their evaluations were based on school self-review questionnaires. ERO draws attention in these evaluations to a requirement for the leadership of schools to demonstrate inclusive values and to fully evaluate the effectiveness of their provisions for students with special needs. This would require schools to make informed decisions about changes needed to improve the achievement and well-being of students with high needs. The comments below from the September 2012 review indicate that many schools are struggling to deliver on *Success for All – Every School, Every Child*.

It is a concern that schools did not identify the impact of their provisions and programmes on the learning outcomes for their ORS students. This suggests that schools are not in a position to know whether the resources supporting ORS students are having the intended impact and are being used in the most effective way. (p. 9)

The conclusion I draw from these evaluations by ERO in relation to the findings in our study is that secondary schools continue to demonstrate a widely differing interpretation of what constitutes inclusive practice and its impact on students with learning disability. This can be seen in what Slee (2001b) refers to as “technist assimilation.” This section has implicated a number of issues that cast students with learning disability as strangers to the mainstream secondary school system. They are physical and social isolation, a lack of whole-school approach to learning and achievement and the requirement for the leadership and school community to value these students contribution. All these issues indicate an underdeveloped notion of what an inclusive school is or, as Slee views it, the kind of school worthy of the inclusion of all students. This highlights that New Zealand government policy has not really provided a definition of what is meant by inclusion that schools could then use to develop their programmes and practice (Macartney, 2009).

The fact that only 34 out of 254 schools evaluated in the September 2012 ERO report were secondary suggests a rather limited picture of what is really happening within secondary schools in regard to the inclusion of students with learning disability. If the intention of *Success For All – Every School, Every Child* is to be realised and 100% of secondary schools are to demonstrate that they are “inclusive confident,” then the leadership of schools need to ensure they know who their students with learning disability are and be able to demonstrate how the extra resourcing and funding has resulted in improved outcomes. Schools should also report on post-school outcomes for students with learning disability. There also needs to be a far larger sample of secondary schools included in ERO’s review. It is interesting to note that when *Success for All – Every School, Every Child* was developed, the MoE’s original target was for all schools to demonstrate that they were “fully inclusive.” This original target has now been watered down to “mostly inclusive.” Indeed, the latest report (at the time of writing) by ERO (July 2013), *Including Students with High Needs: Primary Schools*, as the title indicates does not now appear to include secondary schools.

Youth Guarantee programme

Student participant (Tane): *I want a trades course and be painter’s mate yes.*

Tane talks about his goal to be a painter and how he wants to do a trades course. He describes wanting to be a “painter’s mate,” conveying an understanding about work as a process and the need to start with training on the job. He also uses the correct language, as with “trades course.” Tane’s aspirations are typical of many young people who wish to follow a vocational trades training route post school.

In relation to this student’s aspiration, one of the MoE’s ongoing flagship programmes, the *Youth Guarantee*, provides foundation education to enable young people to transition to further education and participate in the workforce. The *Youth Guarantee* programme replaced the MoE’s Schools Plus programme and aims to raise the educational achievement of young people, with the goal of all students achieving at NCEA level 2 or an equivalent tertiary qualification. A key part of the initiative is to provide fees-free, skills-based tertiary study for 16 and 17 year olds at levels 1–3. In 2010, government established 2,000 fees-free *Youth Guarantee* tertiary places, and this increased to 2,500 in 2011.

Student participant (Tane): ... *yes mum took us down there [name of tertiary college] they said I couldn’t do it because I won’t get level 2.*

Tane was “achieving” below NCEA level 1 and therefore was excluded from the opportunity to pursue his goal under the *Youth Guarantee* programme. None of the student participants will achieve at NCEA level 2 in its current form and are therefore excluded from the opportunity to take part in the programme of training targeted at marginalised groups of young people at risk of NEET. The importance of this cannot be underestimated as this is a key government programme by its MoE to combat high youth unemployment and provide clear vocational pathways into further education, training and employment. The MoE’s *Youth Guarantee* website defines vocational pathways as the move from education to employment in the following way.

The Vocational Pathways are a new tool that provides a clear framework for vocational options, support better programme design and careers advice, and improve the links between education and employment.

accessed on 26/03/2013 at: <http://youthguarantee.net.nz/vocational-pathways>

This suggests to me that vocational pathways for students with learning disability are different to those for mainstream students. Firstly, students with learning disability cannot access the *Youth Guarantee* programme because it targets students who are working at or around NCEA Level 2. Secondly, as described in Chapter 5, students with learning disability rarely transition from education into employment; instead, they mostly transition directly into vocational service day centres, which, I would argue, is not an authentic vocational pathway. Thirdly, it is the MSD-funded vocational services and not the MoE who mostly provide transition support for students with learning disability in their last year of school. As highlighted in Chapter 5, this usually results in students transitioning into MSD-funded vocational day services. All this valuable new policy work under the *Youth Guarantee* programme is denied students with learning disability.

Collaboration for Success: Guidelines for IEPs

Student participant (Claire): signed “*mum*” and “*go*” when asked whether she attended her IEP meeting.

Claire did not attend her own IEP meeting and signed that her mother had gone. A student attending their own IEP meeting is still not happening in all cases. The National Administration Guidelines (NAGs) (2008) provide the policy framework for IEPs in New Zealand schools. According to the NAGs, every school must develop and implement its students’ educational programmes, including those in IEPs. NAG 1 requires that all boards of trustees, through the principal and staff, identify and support students with special education needs (Ministry of Education, 2008).

Recently, of relevance to transition planning, the MoE has produced new guidelines on IEPs titled *Collaboration for Success* (Ministry of Education, 2011). The resource replaced the 1998 Individual Education Programme (IEP) Guidelines (referred to as the IEP Guidelines). It was intended as a compact reference to current New Zealand research, policy and effective practice in supporting students with special education needs.

Student participant (Hare): *I sat and they talked and I never even seen half of em before.*

Hare's description of his IEP meeting conjures up a powerful image of professional control where a student sits among a group of often unfamiliar professionals who are discussing him. As described in Chapter 2, it is only in recent years that students with learning disability from the LSTS schools have been attending their own planning meetings (Gladstone & Thomas, 2009) let alone taking an active and meaningful part. Macartney (2009) considers that IEPs are essentially premised on the medical model where the student's problem can be resolved by professional intervention.

Mitchell, Morton and Hornby (2010) in their literature review for *Collaboration for Success* found that schools still largely viewed the IEP process as the mechanism for educational, legal, planning, accountability, placement and resource allocation purposes. Conversations with many parents of students from the LSTS schools lead me to believe they also see it in much the same way. In addition, Mitchell et al. found little evidence of the efficacy of IEPs to support learning outcomes for students (p. 17). It is my contention that the student with learning disability may be the focus of the professional's engagement but they have very little control or understanding in what is often an overly bureaucratic process (Thoma, Rogan, & Baker, 2001). Students with learning disability most often have a passive role in the meetings as indicated by Hare's comments above and also found in a study by Collet-Klingenberg (1998). For students with learning disability to be actively involved in the process of determining their future requires the professionals to firstly recognise their position of power and then to support collaborative decision-making instead of viewing it purely as an administrative process (Grigal, Test, Beattie & Wood, 1997). For students with learning disability to gain a sense of agency in the IEP process would require the students to take an active and meaningful part (Konrad, 2008). This would require an investment in time by the professionals involved, particularly prior planning and perhaps innovative use of information technology. All this would require a robust programme of professional development for teachers to support the effective implementation of *Collaboration for Success*.

Collaboration for Success guidance also fails to adequately define the relationship between the IEP and transition planning processes. The recent guidelines only state:

Transitions include times when a student enters school, changes class, changes school, or prepares to leave school. IEPs can be designed specifically for these

transitions. When this is the case, they are sometimes called Individual Transition Plans. (p. 7)

Changing the name from IEP to Individual Transition Plan does not provide everyone involved in the process with an understanding of the important school cultural shift and investment in time that is required. The guidelines recommend a lead teacher in secondary schools taking a coordinating role for the many reports and professionals involved. This follows international best practice (Mitchell et al., 2010). I would argue this should be the career specialist, but my experience suggests it would not be because they rarely come into contact with students with learning disability as highlighted in Chapter 5. It is usually the SENCO, unit or learning support teacher. The career specialist having at least joint responsibility for transition planning with the specialist professional would begin to support a more collaborative whole-school approach. Each professional sharing their expertise would be beneficial. Even so, there would still be a need to move from a professionally controlled process to a holistic student/family-centred process. This will help prevent the students in this study feeling alienated from the process, as in the comments by Shane below.

Student participant (Shane): *I go to my meetings now yes but nothing happens after [pause] yes I was gonna do work experience you know.*

Shane conveys the sense that he has only recently started attending his meetings and yet “*nothing happens*” as a result. Anecdotal evidence suggests it had been decided at the meeting that he would undertake some work experience but this it didn’t eventuate. In order for students with learning disability to be actively involved in the transition planning process, this requires high levels of expertise but also the right attitude, values and a commitment to shift control from the professional to the young person and their family through the process. Starting early in the transition planning process is a critical aspect in effectively supporting the students (Cleland et al., 2008). My experience is that schools often leave transition planning for students with learning disability until the last year which acts against successful transitions. We have to believe that the students’ dreams, goals and aspirations can be realised and a pathway planned to support them in their journey towards it. We require a process that is less driven by bureaucracy and professional control. How *Collaboration for Success* is interpreted and utilised in New Zealand secondary schools will have a direct influence on career and transition planning. Without a programme of professional

development, it will be a challenge for schools to avoid using the guidelines as anything other than what Mitchell et al. (2010) viewed as often conflicting educational, legal, planning, accountability, placement and resource allocation purposes.

Career and transition education policy work

Recently, there has been a good deal of interest in how career and transition education can be better utilised to support those students at the margins of the education system. This as described in Chapter 2 as the result of worrying levels of youth unemployment in New Zealand and the intergenerational trends emerging (Nairn et al., 2012). A research programme on Education Employment Linkages (EEL) explored these issues in a collaborative project of the AERU Research Centre of Lincoln University and the New Zealand Council for Educational Research in Wellington. The EEL was a longitudinal study to understand these trends and support solutions in New Zealand to youth unemployment that is endemic across most OECD countries. The research had its origins in the National Career Education Survey in 2007. I attended the EEL colloquium in Wellington in August 2012 where cross-sector leaders came together to hear the research project findings and discuss collaborative solutions to how all youth can make successful transitions from education into employment. The EEL has produced a variety of publications, seminars and presentations over the life of the project and yet students with disability have been conspicuous by their absence from this extensive work. I contend that this is as a result of the perception that students with learning disability do not require a career as they rarely follow the further education, training or employment pathway. The word “career” becomes an important indicator for gauging if students with learning disability are excluded from the mainstream transition processes. I now briefly discuss the implications for specific work related to careers and transition.

NZCER Survey of Careers Education in Schools and the Creating Pathways and Building Lives (CPaBL) project (2007a)

Student participant (Joy): *I'm capable I know that I can have a career with help.*

The student's comment above including the word "*capable*" is relevant in relation to a project concerned with supporting pathways from school. It is also a key word in this thesis. The capabilities of students with learning disability are not often considered in relation to planning that leads to further education, training and employment. Instead, the focus is on an alternative transition pathway typified by the tension between the supports required and the services available. The New Zealand Council for Educational Research (NZCER) survey of *Careers Education in New Zealand Schools* (2007) reported "patchy practice and a lack of co-ordination in careers education" generally. The primary motivation for this report was a number of New Zealand research studies and evaluations which concluded that careers guidance delivery was haphazard in some schools (Vaughan & Boyd, 2004, Vaughan, 2007). *Creating Pathways and Building Lives* (CPaBL) (2007a) was a 2 year MoE project that evolved from the aforementioned national survey, aimed at building a sustainable, integrated school-wide approach to career education in 100 secondary schools selected by the Ministry and not included in the original 2007 *Survey of Careers Education* sample.

It is striking that this significant project considered every marginalised group in New Zealand but did not specifically include students with disability, let alone students with learning disability. Interestingly, the final reports to come out of this project highlighted the challenges with the ERO evaluation of the CPaBL project in 2009:

Students with special needs and students with disabilities were mentioned in the initial documentation, but no provisions were made for them in the implementation process, and few schools identified them amongst their students at risk. (p.8)

To consider students with disability as not at risk encapsulates how schools really position and value this group of young people, their capabilities and more specifically their expected transition pathway. It provides further evidence for students with learning disability being positioned as strangers to careers and transition education policy work. It requires the leadership of schools to consider their school culture, values and how they meet the diversity of the student population within education and the wider community (Barton, 1997; Goodley & Runswick-Cole, 2010; Runswick-Cole, 2011). It also points to the difficulty schools have

with including students with learning disability in their overall school structures and systems. The fact that students with learning disability were mostly not considered in the policy work on careers and transition education acts to position them as strangers. As suggested, they do not appear in the career surveys because it is rarely considered that they require a career, since it is not expected for them to enter further education, training or employment.

ERO Review of Careers Information, Advice, Guidance and Education (CIAGE)

Student participant (John): *I never seen the careers woman she doesn't come here [to the special unit] and I've never been there [careers office].*

The comment above by a student from a special unit in a secondary school reinforces my professional experience that students with learning disability rarely come into contact with careers specialists. More importantly, it supports a view that the student does not come into contact with the wider school systems, specifically the new systems and whole-school approaches being developed related to CIAGE. The comments reveal the isolated nature of students with learning disability from a special unit in the mainstream secondary school. The Review of Careers Information, Advice, Guidance and Education (2012) was ERO's first national report on CIAGE since *The Quality of Career Education and Guidance in Schools* (2006). In that report, ERO used a different framework for evaluation to that used in the CIAGE review. As a result, they stated it was not possible to measure the extent of any systemic changes in careers education during the last 6 years. However, they still stated that

it was evident that significant system-wide improvements in CIAGE will require schools to move from having efficient careers departments to having innovative school-wide systems and processes that are consistent with those developed by a small group of schools in this evaluation. This potentially represents a significant shift for schools and policy-makers, as it involves a broad range of secondary school staff actively supporting students to develop career management competencies, and focusing on their futures. (ERO, 2012, p. 2)

Where do students with learning disability fit into this “significant shift” if they are not identified as part of the mainstream of secondary school systems? The challenge by ERO for secondary schools to have a “whole-school” integrated approach to CIAGE is welcome. ERO highlighted the policy and school wide shift required:

A significant system-wide improvement in the approach taken to CIAGE would require schools to adopt a more innovative whole-school approach focused on student futures. This represents a considerable challenge for schools and policy-makers. The professional development and school-change implications involve a move from an approach based around the work of a careers department to one that involves most, if not all, teachers significantly contributing to CIAGE. (p. 22)

The schools that ERO found to have the highest quality approaches to CIAGE were focused on students' futures. These schools had well-trained staff across the whole-school. Importantly, effective relationships were at the core of what ERO considered best practice. Staff had developed excellent relationships with students and actively supported them to develop goals, understand themselves, investigate opportunities and make decisions. However, out of the 44 secondary schools reviewed, only 4 – or 12% – had high quality CIAGE (ERO, 2012, p. 1). This by any measure is a damning indictment of how well secondary schools prepare all students for transitioning from school, let alone students with learning disability. The report mentioned the need to focus on priority groups, referring only to Maori and Pacifica students as a marginalised group. Students with disability were not mentioned. ERO found that many schools did not focus on careers education until students were in their last year of school. Of significance to students with learning disability, the report states that "at Years 11 and 12, STAR and Gateway programmes were often implemented independently of the careers advisor" (p. 20). My experience has been that most transition support for students with learning disability has been provided through STAR funding. The fact that ERO found the STAR programme was often implemented independently of the career advisors in schools is further evidence to support my argument that students with learning disability do not feature in how schools implement their CIAGE, which acts to exclude them and cast them as strangers.

Careers New Zealand: Career Education Benchmarks

Student participant (Susan): ... *I'd like a career thingy she said [pause] who's gonna help me though?*

Susan's comments on how she would like "*a career thingy*" raises a pertinent question she herself asks "*who's gonna help me though?*" Her comments support the argument I am

constructing that students with learning disability are mostly not considered to require a career and as a result rarely come into contact with mainstream school systems, particularly CIAGE. Susan's question raises an issue highlighted earlier concerning who should take responsibility over the transition process for students with learning disability. It is clear from the findings that special education professionals and contracted vocational service workers have historically done so, mostly in the student's last year of secondary education.

The Career Education Benchmarks programme was designed by Careers New Zealand in 2011 to help provide a shared appreciation of what effective practice in career education requires. It is a school self-review tool enabling Careers New Zealand to encourage more consistent practice and smoother transitions for students from school. There is a move from the term "career adviser" to "career specialist," recognising the complexity of schools and society today and that multiple roles may come under the job description for the person coordinating effective career education. Careers New Zealand recommends a senior manager take overall responsibility.

The Benchmarks are a flexible tool that enables schools to use the best approach that suits their needs. Careers New Zealand guidance on their use suggests:

A team approach should be used for the self-review where trustees, the principal, senior managers and school leaders, the career development specialist, and career development staff work collaboratively. Schools should task a member of their senior leadership team with overseeing and coordinating career education across the school and supporting specialist staff (obtained at: <http://www2.careers.govt.nz/educators-practitioners/planning/benchmarks>).

The involvement of the school leadership in the review is pertinent, as is the recommendation for a collaborative, whole-school approach with full representation of the school community. However, there is only brief reference to students with special education needs:

Students with special education needs are less likely than their non-disabled peers to go into employment, training or tertiary education when they leave school. It is important that these students are included in the provision of career education in schools in line with *Success for All – Every School, Every Child*. In support of this, the Ministry of Education has developed best practice guidelines for ensuring effective transitions for students with special education needs. (p. 5)

This again reinforces the position that students with learning disability follow alternative pathways to those for students without disability. By referring schools to the MoE's best practice guidelines on effective transitions for students with special education needs, it is again signalled that students with learning disability do not require a career because they will not go into further education, training or employment like students without disability. It also masks the reality that students with special education needs are a heterogeneous group, as are students with learning disability. The best practice guidelines referred to are the *National Transition Guidelines for special educators, schools and parents* (2012). I attend to this resource in the next section.

The Benchmarks are an excellent resource for schools to support their self-review process, encouraging a whole-school approach to career and transition education. The mention of students with special needs and the referral to the National Transition Guidelines developed by the MoE is relevant. However, again the inference is that students with learning disability and indeed those with special educational needs generally will somehow achieve successful transitions by schools using the National Transition Guidelines and not the whole-school career approach advocated by the Benchmarks.

This policy work again defers schools to supplementary guidance. Guidance is only as effective as the inclusive and democratic structures and systems embedded in schools to ensure all students have equity in access and resourcing. I suggest this again reinforces the argument that students with learning disability follow a separate transition pathway and process, casting them again as strangers to the mainstream secondary school process.

National Transition Guidelines for special educators, schools and parents

Student participant (Rua): *I think I'm going to transition someone will help me*
[pause] I think?

Rua's comment reflects further the lack of structure to the transition process that might support her. The student's confusion over the process and whether anyone will help her is revealing. Another initiative arising from the Government's *Success for All – Every School, Every Child* work programme is the transition guidelines produced by the MoE to help schools with transitions from school to post-school life, titled *National Transition Guidelines*

for specialist educators, schools and parents (2012). The guidelines include 10 best practice principles and what they mean for school staff. These guidelines have been taken from international best practice and New Zealand research, including the Wayne Francis Charitable Trust transition research in Christchurch (Cleland et al., 2008) that produced the best practice framework that these guidelines are largely based on. The guidelines also draw from the best practice of the LSTS. The information in the guidelines provides useful information on practice for all staff, particularly careers staff.

However, the guidelines still give the impression they are for special educators. By this I mean they are not explicit enough in promoting a whole-school responsibility for students with learning disability. Career specialist leadership should be made explicit in the guidelines. This is clearly evident from the title of the resource: *National Transition Guidelines for **special educators** (my emphasis), schools and parents*. Whether careers staff in secondary schools will view it as something for them is immediately open to interpretation because of the title. These seemingly small matters all act against a whole-school responsibility for the transition of students with learning disability. The underlying intent of the guidelines is that it is still the responsibility of special education staff to work with these students during their transition. This could mean that the valuable resources available from the career specialist and its wider networks are lost. Equally, the valuable exchange of expertise between the career specialist and special educator and others in best supporting the student may be missed. This would begin to embed a whole-school responsibility for all students rather than “special students” being the sole responsibility of the special education staff.

The MoE has been attempting to address careers guidance as “weakly professionalised” since an OECD report on New Zealand in 2004. I have begun to make the case that students with learning disability are strangers in relation to what has been a good deal of policy work in the area of careers and transition. The flagship programme of work under *Success for All – Every School, Every Child*, as mentioned in Chapter 2, has a number of initiatives to support 100% of schools being able to demonstrate they are fully inclusive by 2014 (MoE, 2010a). The programme is aimed at realising the Ministry’s vision of a fully inclusive society. The interesting thing to note is that all schools are now only required to demonstrate “inclusive” practice, as opposed to “fully inclusive” practice as initially announced by the then-education

minister, the Honourable Rodney Hide. ERO's follow up reports in 2012 (2012a & b) and 2013 illustrate the relatively small number of secondary schools evaluated. Students with special needs were rarely mentioned by schools in their self-review responses, particularly regarding achievement. This suggests a picture of secondary schools where students with learning disability are mostly excluded from the impact of all this policy work.

What emerges is that all this ongoing policy work fails to provide a flexible pathway into further education, training and employment for students with learning disability. The findings in Chapter 5 clearly articulated that this was what the students with learning disability wanted. ERO in New Zealand (2013a) undertook a national evaluation of schools' systems, processes, initiatives and curricula aimed to support all students in education, employment or training as part of the Government's *Youth Guarantee* policy. The key question in this evaluation was: how well are secondary schools preparing senior students for their future education, training and employment? By any measure, students with learning disability are "missing in action."

Thus far in this chapter the findings indicate that students with learning disability are mostly excluded from mainstream school processes, particularly those related to careers and transition. This is in part because there is a lack of a whole-school approach to CIAGE in schools. The word "career" is not often used in the transition of students with learning disability. Career specialists do not often work with students with learning disability. Schools do not often report on progress for students with learning disability in terms of career-focused achievement. Students with learning disability are excluded from flagship MoE programmes like *Youth Guarantee* that are focused on further education, training and employment. I contend that this is because there is an expectation that students with learning disability follow a different vocational pathway. All this positions students with learning disability as strangers in relation to policy work on careers and transition. In Part 2, I now explore how students with learning disability are positioned at the micro level in schools.

STRANGERS AT THE MICRO LEVEL

In Part 1 of this chapter, I argued that students with learning disability are strangers at the macro level to education policy, specifically policy work related to careers and transition for all students. I suggested that there is a lack of their meaningful presence and consideration in policy work, and I will now explore whether this has a direct influence on how their presence is defined in schools at the micro level. I argued that at the macro policy level, students with learning disability are not considered within the mainstream framework for all students. This appears to be true whether those students are educated in a special school or special unit or a learning support setting in a mainstream school. This disjointed policy environment manifests itself in parallel systems that act to keep students with learning disability as strangers to mainstream secondary school practices. This signals differing professional control, attitudes and low expectations that lead to limited pathways from school.

In the next sections, I present findings at the micro level according to the following themes related to the findings in Part 1:

- Professional control
- Limited interaction with mainstream career services
- Limited transition planning in schools
- Multiple plans, restrictive pathways

Professional control

Student participant (Mary): *She doesn't give me much credit, she says to me you are not allowed to do this and do that and you are so and so blah, blah, blah.*

Mary's comment highlights the pervasive control over the student participants by specialist professionals, namely special school staff or mainstream secondary school special unit and learning support class staff. The student was referring to her learning support teacher and a discussion about work experience. The teacher's response to Mary shows a disciplinary, controlling regime in the decision-making process and highlights a failure to acknowledge the

student as a valid negotiator of her life. The short excerpt below from the first student focus group further illustrates professional control over the transition process.

Interviewer (Caroline): *What will you do when you leave school?*

Student participant (Pete): *I'm going down to [name of vocational day service].*

Interviewer (Colin): *What do you think about that?*

Student participant (Pete): *Don't know they never asked me [pause] Mum told me.*

Pete's comments reinforce the professional control over the decision-making process. Pete is aware of his lack of control and is not sure how he feels about it, as shown in his use of "don't know," but thinks that they at least should have been asked. The fact it was his mother who informed him about where he was going after school illustrates the general lack of student voice in the transition process and the lack of student-centred planning. It also alludes to a common tension between what the parent desires and wants for their young person as opposed to what they might want. The student with learning disability often desires risk and freedom against the parent opting for safety and security. This can be described as the tension between freedom and constraint. This manifests itself in the parent's desire to opt for the perceived safe and secure environment of a regular vocational day placement Monday to Friday. This has been a common decision made by parents in countless conversations I have had with them over the years at a student's transition planning meetings.

Jack: *Yes [name of staff] tells me what I'm doing for work experience.*

The comment above from Jack was one of a number related to staff control of the decision-making process within the special school setting. It was the staff member who decided what work experience Jack was going to do. I knew from my familiarity with the special school setting that this particular school had a member of staff recently appointed as transition coordinator. This staff member was extremely diligent and hard working and provided a wide and varied range of work experiences for the students while they were at school. Opportunities for students to undertake work experience were arguably far more than most other schools locally because of this dedicated position. However, the opportunities were

generally those the staff member considered were appropriate work experiences for a particular student and not theirs or derived from effective person-centred planning. The situation arises where the school has a limited range of work experience placements that the students are slotted into year after year as opposed to work experiences being generated from transition goal-setting founded on the student's aspirations and capabilities. This situation exemplifies a medical/deficit model where the specialist professional is in control of the decision-making processes. This is further illustrated by Susan's comment:

Student participant (Susan): *[Name] gives me my work experience yes.*

The staff member worked in a special school and, very much as has been described in earlier parts of the thesis, was exposed to deficit model philosophies and practices that manifested themselves in a caring and supportive way but reinforced a deficit, controlling regime. What Susan meant by "*[Name] gives me my work experience*" can be viewed as her having little control over what work experiences she undertook. Again, this indicates a lack of student agency in the transition process.

Limited interaction with mainstream career services

Student participant (Rua): *I never seen her she does careers [pause] I think.*

Rua was a student in a special unit on a mainstream secondary school site. Her comment reinforces the lack of input career specialists played in her transition experience. Crucially, this lack of involvement results in a potential key resource in secondary schools for students with learning disability being lost. This situation is further highlighted in the comment below, where Rua doesn't even know where the careers office is despite having been at the school for five years.

Student participant (Rua): *... don't know really [where] the office is.*

The students in this study from mainstream secondary schools rarely came into contact with staff other than those from the unit or learning support classes. Career specialists do not work with students with learning disability, and I suggest this position might come from their perception and expectation that students with learning disability should and will follow a

different pathway, mostly into a vocational service day centre. Other areas of the student's life are also not taken much into consideration. This was highlighted earlier in the chapter when ERO reported that secondary school teachers believed these students should be educated in special units. Opportunities for the students to follow their goals into further education, training and employment are not realised.

There are tensions at play where the attitudes and perceptions of career staff collide with constraints on their often limited time and resources.

Student participant (Pete): *Miss [name] she never turned up for my meeting [pause] she didn't have time she said.*

This was the only instance from the focus groups where a career teacher was mentioned in relation to students with learning disability. The career teacher failing to turn up for Pete's IEP meeting might further illustrate the tensions regarding resourcing and time constraints but also perhaps concerning staff attitudes. This was in a school that had a well-regarded careers department. However, one might also draw the conclusion that this may support the earlier finding that career specialists consider students with learning disability to follow a fixed pathway into a vocational day service and so do not require their input. Careers specialists are focused on those students who are transitioning to further education, training and employment, particularly for those marginalised groups named under the *Youth Guarantee* programme.

If students with learning disability are “out of sight” in segregated settings, whether special schools, special units or learning support classes on a mainstream site, they might also be “out of mind.” Additionally, self-governing schools has meant a wide variance in how CAIGE is resourced in schools and how school leadership prioritises careers, as found by ERO (2012). Individual school interpretations impact what a careers department might look like in terms of resourcing and staffing and which students they prioritise as a result. As an example, the schools supported by the LSTS Service varied from one school with 6 hours of teacher time per week allocated for a thousand students to another where they had 2.2 full-time equivalent teachers employed for a similar role. This widely differing career resourcing situation is bound to influence delivery and practice in schools and will act to exclude students with learning disability from CAIGE. The result is that students with learning

disability remain the responsibility of specialist professionals. This then acts to absolve the careers specialists from what should be their responsibility to work with all students.

Limited transition planning in schools

Student participant (Mary): *I went to my IEP, lots people there and I never said zip.*

The comment above by Mary, who attended her IEP meeting, illustrates that although she was physically present she felt little ownership or control over the meeting. The student was attending a special school and her observation of the meeting where she was silent amid the “expert” voices reinforces the professional control over the planning process that still persists in schools today. This supports findings by the LSTS (Gladstone & Thomas, 2009) and others (Konrad, 2008) where meaningful and active participation by the student with learning disability was unusual. A common issue with transition planning for students with learning disability is that the process is started too late and often not until the last year of secondary school.

Student participant (Mary): *Mum says it's too late I'm leaving school anyway [pause] she told them that at the meeting.*

The process is often also controlled and managed by external agencies, as with the MSD transition contract that vocational and supported employment services currently hold in Christchurch. This provides a contract to work with ORS-funded students in their last year at school. Mary's comments about her mother's views support my experience that despite best practice evidence to the contrary, schools still mostly begin the process far too late in a student's transition.

Student participant (Jack): *I leaving soon I still doing English and maths IEP targets I think [pause] I leaving you know yes [pause] I need skills.*

Jack's comments raise an important issue concerning the relationship between the IEP and transition planning processes that causes much confusion. As highlighted earlier in this chapter, the IEP remains largely a platform for professionals to make decisions about resourcing, accountability and funding rather than about how in the later secondary years it

can support effective transitions utilising a student/family-centred approach. Jack's comment illustrates the general confusion with the current process when he talks about curriculum targets "*I think.*" As Jack was in his last year at school, his comment concerning English and maths IEP targets and how he repeats that he is leaving give the impression that he is apprehensive about it. He appears to be saying that he should be focusing on other matters than his English and maths targets. Numeracy and literacy have been found to be important elements in transition focused education (Kohler, 1996) but I have experienced many times when a student has been working for years on similar maths or English targets that they don't consider relevant. Jack's comment also highlights the confusion between curriculum targets and transition planning goals. His evident insight in many ways cuts through the common confusion concerning how and when the IEP focus should change to focus on transition. His comments appear to convey his realisation that time is running out.

Jack's comment "*I need skills*" can be seen to represent a special education perspective where choice, independence and being more self-determined are often interpreted by teachers as achieved through functional skills-based learning taught in isolation.

Multiple plans, restrictive pathways

Because there are usually many agencies and services supporting a student with learning disability, there often are multiple plans involved. This causes confusion and acts against a student/family-centred approach. I have already highlighted the confusion with the IEP planning process in relation to the transition process.

Student participant (Pete): *[Name] got my plan he said and the centre wants to do me one as well ... It's all plans you know.*

Interviewer (Colin): *Have you seen your plan?*

Student participant (Pete): *Don't think so no [pause] which one?*

Pete is talking about an MSD-contracted service worker who is working with him in his last year of school. That he has not seen the plan is common and shows the lack of ownership the student feels in the process. Pete also makes the comment "*which one*" to underline the confusion often present. It reinforces my experience the contract is utilised mostly to access

milestone payments for the service under the MSD contract. Pete was due to attend a local vocational day service after school and his comment about them also wanting a plan illustrates a lack of collaboration in the process. The planning process is one that fulfils the service's needs rather than the young persons. This situation is not surprising as the service contract and the milestone payment process encourage this practice to ensure payment. This can be seen as evidence of the individualised and marketised approach to social welfare service delivery.

As manager of the LSTS, my experience supports the findings from our study where the future lives of students with learning disability are often controlled and managed by a range of special education and social welfare services and agencies that all have their own plan for the student and young person with learning disability. There is very little of the continuity or collaboration in these plans that might result in enhancing the person's journey towards a good life. This situation mostly arises out of the way services are contracted and can also be described as the "silo mentality" in government department funding. With the current MSD transition contract, the service receives their funding based on signing up a student and then drawing up a transition plan as two of the four milestone payments. This plan is then service-orientated rather than student/family-centred and becomes a tool for accessing funding rather than a plan for how best to support the young person in their journey towards a good life. This can be seen as the commoditisation of young people with learning disability.

Thus far I have attempted to connect the young people's views with related education policy and practice. I have also tried to demonstrate through the findings how students are heavily influenced at the micro level by professional discourses in the transition process that perpetuate special education philosophies and practices. I have showed that students with learning disability rarely come into contact with career specialists, whether in a special or mainstream school setting. Consequently, the word "career" is not one usually associated with these students, and I suggest that this significantly acts to lower expectations for students with learning disability among regular school staff as well as the special education professionals and others who overwhelmingly work with them. Importantly, the findings illustrate the lack of a whole-school approach to working with students with learning disability. The leadership of schools should take responsibility for promoting a whole-school

approach. This is supported by ERO's (2012, 1 & 2) report findings related to how well schools are preparing students for further education, training and employment.

I have also suggested through the findings that the transition planning process is often started much too late and fails to put the student with learning disability at the centre of this process. In addition, the planning is confused by a number of factors. There is confusion among school professionals and a fundamental difference concerning the relationship between the IEP and the transition planning process. The IEP process is often one of accountability, funding and resource allocation in the secondary school that despite new guidance acts against a process that provides pathways as students with learning disability enter the last few years of secondary education.

Chapter summary

Findings suggest students with learning disability are consigned to the margins of the education system, being overwhelmingly to be found in special schools, special units or learning support classes on mainstream secondary school sites. Not one student in this study was in or attached to a mainstream class, other than one student who was assigned a form class. This is the typical situation in New Zealand for secondary-aged students with learning disability, although a small minority might attend specific lessons, often on an informal basis. I maintain that this signals to the mainstream of education that it does not need to consider these students other than in terms of special education, resources allocation and funding. This is not about the quality of teaching offered by special education or necessarily curriculum. Importantly, this is about whether students with learning disability have the opportunity to benefit from mainstream processes and structures, particularly career education and transition pathways into further education, training and employment as appropriate. The findings suggest that students with learning disability transitioning from special education transition programmes do not.

In this chapter, I focused firstly on education policy to highlight systemic issues resulting in an exclusionary landscape for students with learning disability as they transition from school. Despite numerous policy initiatives aimed at improving the transition for all students, particularly those at risk of not transitioning successfully, students with learning disability

remain strangers with regard to this policy work. In exposing this situation, I suggest that at a surface level it is partly founded on a lack of understanding by policy officials and school leaders about whom exactly this group of students are, the nature of their capabilities and how best to support them. As the ERO found in recent reports, schools often failed to report on these students' learning or achievement. This may be because these students are mostly subsumed under the broader label of students with disability.

However, I suggest that it is also about education policy that fails to meaningfully consider this group of young people as capable and competent. The findings suggest that this may be a systemic problem related to deficit assumptions and attitudes; low expectations; and ingrained pathways for these young people that mostly lead into vocational service day centres. This is an important point as it highlights the resilience of special education processes and structures that act to position students with learning disability as strangers to the mainstream secondary school career and transition process for students without disability. As special education services and bureaucracies have historically managed and controlled these students this has perhaps allowed secondary schools "off the hook." I contend that there has been an expectation created by related education policy and promoted among special education services and their professionals that students with learning disability should and will transition into vocational day services. As highlighted in Chapter 5, this is not what the majority of students want. This is irrespective of whether the student attends a special school or a secondary school. This systemic problem is not about setting, as in the contradiction of special schools in an inclusive policy landscape (McMenamin, 2014). It is fundamentally concerned with how we value a particular group of students.

It is also the case that in a neoliberal competitive contracting market, vocational services are reliant on students transitioning into their services for funding and survival. As manager of LSTS, I had firsthand experience of how local vocational services operated in a climate of anxiety related to whether their contracts with the MSD would be renewed. The power was held by the contracting bureaucrats. In addition, the vocational service transition workers were always anxious about signing up enough clients to make their position financially viable. Anecdotally, I saw how managers of local vocational services found it difficult to operate in a climate of mutual trust and collaboration because of the competitive contracting

environment created by government policy and the service contracts that were competitively tendered.

Tertiary education and paid employment are rarely considered for students with learning disability when there is an expectation by policymakers, professionals and parents (albeit for different reasons) that they will transition directly into vocational services. If their transition pathway is already mapped out and leads into the local vocational day service, then it is hardly surprising that schools do not often consider that young people with learning disability require a “career.”

Additionally, the findings might point to a more deliberate and troubling scenario where policy officials have concluded that students with learning disability do not require a “career” and therefore do not need to be included in the same career and transition framework as students without disability. This describes students with learning disability being collateral damage in the wider drive in education policy around marginalised students. They do not require a “career” as they are already immersed in the welfare benefit system, a system I suggest they are constrained by rather than benefit from. The word “career” is important here as the language of special education (Corbett, 1996) is a powerful exclusionary tool, making me question how often the word “career” and students with learning disability are used simultaneously. The word “transition” became synonymous across Western countries with planning for post-school provision and students with learning disability, but rarely is the word “career” used alongside. Transition is touted in policy terms as meaning the support required to be independent, make choices, be present and participate in the community. The reality is that students with learning disability move from school into vocational day services with little independence, no choice, some presence and not much participation.

An illustration of how students with learning disability have been “missing in action” (Bauman, 2011) regarding recent education policy work is the Education Employment Linkages (EEL) longitudinal research programme. The EEL held a colloquium recently in Wellington (August 2012) where it brought together leaders in the field of youth transitions to discuss the findings from almost five years of research inquiry. I was invited to attend with Grant Cleland, a person with a disability and activist who is now CEO of a large government-funded employment agency. The research team’s work was founded on the question: how can

formal support systems best help young New Zealanders make good education employment linkages to benefit themselves, their communities and the national economy? Findings highlighted the non-linear process and troubled journey for many youth from education into employment. There was a focus on understanding how marginalised young people could be supported to find success in this climate. Alarming, students with disability and therefore those with learning disability were not even considered within the extensive and extended research programme over many years in New Zealand. I drew the conclusion that because students with learning disability are not making the link between education and employment, they do not need to feature. I drew attention to this fact in the plenary session at the colloquium and was met by a response best described as “much sympathy but little understanding” and an expression that raised the question, “Why would they need to make the link between education and employment?” The fact that Grant and I were invited makes me suspicious of the intent and I was left with the view that we were there to just “tick the disability box.”

In Chapter 7, the third and final findings chapter, I present the findings from the research team journey. The chapter describes “the relational dimension” as the story of how Andrew, Caroline and I meaningfully collaborated as research team members to co-conduct this study. It provides some solutions that act to resist the exclusionary landscape that positions these young people as strangers to secondary schools and the wider community. It offers an alternative to professional control and demonstrates how these young people can not only meaningfully participate in research about their lives but also make the journey towards a good life, as judged by them. The chapter ends with a focus on the importance of interdependence and a sense of belonging as a positive response to exclusion, professional control and unrealised lives.

CHAPTER 7: THE RELATIONAL DIMENSION AND THE RESEARCH TEAM

In this chapter I present the relational dimension as an alternative to a positioning of young people with learning disability as *strangers* in education. The relational dimension provides a counter-narrative to the exclusionary policy and practice landscape and unequal power relations in education described in Chapters 5 and 6. This counter-narrative recognises the unique difference of each individual while acknowledging and promoting all people's relative interdependence. From this perspective students with learning disability are viewed as capable, responsible and contributing who desire greater opportunities to demonstrate leadership through this interdependency in the relational dimension. An ethic of care (Noddings, 1995), risk and moral endeavour are important elements in the relational dimension.

In this chapter I articulate the research journey as about what we have learnt together as central in seeking solutions to how young people with learning disability can find a good life. The lack of effective relationships and collaboration at both the macro and micro level has been shown a key barrier to successful transitioning from school (Bennie, 2006; Bray, 1998, 2003; Cleland et al., 2008; Hornby & Witte, 2008; Mirfin-Veitch, 2003; Mittler, 2007).

In this chapter I draw heavily on first person accounts from Andrew and Caroline through a variety of data sources. I do so to demonstrate the co-leadership and "expert" roles Andrew and Caroline played through the research process. At the micro level this allows for a re-imagining of the relationship between the student/young person with learning disability and the professional "expert" so we are all positioned as "experts." In this sense students with learning disability are viewed as capable and insightful in a relationship that is caring, reciprocal and trusting. There is mutual acknowledgement of the lived experience and expertise we all bring with us. This acknowledgement of expertise has significance for combating low expectations, presumptions of (in)competence. At the macro level it sends a clear message to policymakers through joint presentations at national and international conferences that demonstrate their expertise, advocacy, competence and capabilities.

Transcriptions of research team meetings and training session audio recordings, text and email communications, digital photos of co-researcher diary entries, professional conversations and my personal recollections are all utilised. To further illustrate points, I also present research team dialogue from a transcription of a video recording of our joint presentation made at the Australasian Society of Intellectual Disability (ASID) conference in Brisbane from September 29 to October 1, 2010. The first half of the joint presentation was a PowerPoint designed to give an overview of our research project and preliminary findings and the second half to provide insight to the relational dimension of our research through an unrehearsed discussion, among the three of us, of the different themes we had identified. This method of engaging in open discussion in front of the conference audience had inherent risks; in particular I had to be mindful of Andrew and Caroline's vulnerability. It opens non-disabled researchers up to public scrutiny concerning their ethical, epistemological and methodological positions. It also raises critical questions related to learning disability research concerning "working with the experts" (Knox et al., 2000) and issues on moral and epistemic authority; as Carlson asks, "Who is the expert?" (2010, p. 58). This research has demonstrated we all bring expertise with us.

The research process from design, data collection and analysis, reporting and dissemination is complex, multi-layered and demands some degree of abstraction (Walmsley, 2004). I promote the position that the young people with learning disability in this study have the capacity, capability and, importantly, the desire to actively seek solutions and answers to questions about their lives through meaningful collaboration and the opportunity to play leadership roles in the research process concerning their lives. I would suggest that the more severe the intellectual impairment, the greater the requirement for more innovative research methods, a need for extended timeframes and the more essential a deeper relationship (Booth & Booth, 1996; Gilbert, 2004). Much research has explored how people with learning disability can be involved in research as participants, co-researchers, co-workers or as members of reference groups (Stalker, 1998; Knox et al., 2000; Mactavish et al., 2000; Perry and Felce, 2004; Lewis et al. 2008). This research promoted an active "co-leadership role" within the research team from its earliest stages of development. Our research purpose was a shared one in attempting to find how young people with learning disability can make a successful transition from secondary education in their journey towards a good life.

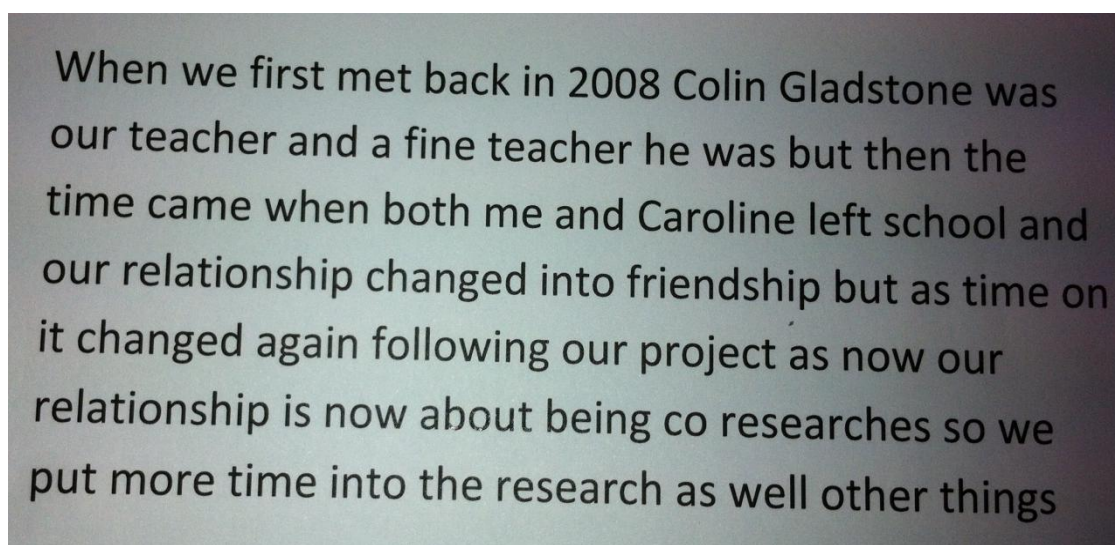
Questions about the nature of the relationship between Andrew, Caroline and I naturally expose much that has been central to the debate within learning disability research. As described in earlier parts of the thesis issues of professional power, control and domination against passivity, silence and acquiescence all have historically defined relationships between young people with learning disability and researchers without disability (Walmsley, 2011; Walmsley & Johnson, 2003). Communication in regard to people with learning disability plays an integral role in how any reciprocal relationship is understood (Knox et al., 2000; Williams, 2011) and was true of ours. The question of access to theorising in learning disability research that moves beyond translating information (plain facts) to an understanding and presenting of abstract thoughts, ideas and solutions to problems is a thorny issue seldom discussed (Walmsley, 2001) but tackled in this chapter through our experiences as co-researchers. I contend it was our capacity for caring in our interactions and the organic evolving nature of our relationship over an extended period beginning before and continuing after the research project that has defined it. We all had to be “in it for the long haul” and through the journey knowledge about possible solutions in learning disability research and transition were gained.

Origins of the research: An evolving relationship

I now focus on the origins of the research study to describe findings related to the nature of our emergent relationship. The origins were threefold as described in Chapter 1. First, was in the many conversations with Andrew, Caroline and their classmates concerning their goals and aspirations and transition experiences when in the teacher/student relationship. Second, the secondary schools transition support group for teachers I set up locally in 2008 as a community of practitioners to provide professional support. Third, the Wayne Francis Charitable Trust Transition Project for Disabled Students and its findings on systemic issues related to transition of students with disability locally.

Our study originated from our own immersion in the transition process at school albeit in the different roles of student and teacher. Andrew and Caroline were experiencing their own transition from secondary education and I, as the transition teacher, was supporting them and their families through the process. I now utilise Andrew and Caroline’s reflective diary entries to describe the origin of our relationship.

Andrew's diary entry (Figure 8) maps our changing relationship from student/teacher to friends and researchers. His comments value our friendship that continued when becoming co-researchers.



When we first met back in 2008 Colin Gladstone was our teacher and a fine teacher he was but then the time came when both me and Caroline left school and our relationship changed into friendship but as time on it changed again following our project as now our relationship is now about being co researches so we put more time into the research as well other things

Figure 8: Reflective account from Andrew's research diary

I felt maintaining contact after Andrew and Caroline had left school was part of my responsibility as the transition teacher. This is an important point as I believe schools should be interested in tracking the post-school pathways of their students as a way of assessing whether they have been effective or not and should inform the school self-review and development process. This is reinforced by ERO's findings in 2012 that very few schools reported on achievement for high needs students.

In another diary entry (Figure 9) Andrew understands and traces the beginning of my PhD studies coinciding with the Wayne Francis Charitable Trust project and then the My Life When I Leave School transition project.

When Colin 1st started his PhD at the university was the formation of a project started out from the Wayne Francis trust project here in [] and then that went onto another project into the my life when I leave school transition project which also started with 2 co researchers Colin and Caroline and of course me

Figure 9: Reflective account from Andrew's research diary

Colin Andrew and I have a relationship within the Team. Colin was a Teacher who taught me and Andrew and others then when we started the research we then came professional in a professional matter but then we all got to know each other a lot then that's how we become friends (very good friends) Andrew and I became friends with Colin's wife (Jill) and his two sons (Nathan, Callum) we often go there for a wine, Beer and have dinner there.

Figure 10: Reflective account from Caroline's research diary

Caroline's diary entry (Figure 10) further describes the evolving nature of our relationship. Evolving from the teacher/student dyad as Caroline described to a professional one "*when we started the research we then became professional in a professional matter.*" She comments how "*then we all got to know each other a lot that's how we became friends.*" Our growing friendship evolved as we spent more time together through the research process. This was also important as she reinforced with her comment "very good friends." Our growing friendship through the research process extended to my family as Caroline described. Developing a more personal relationship with me was important to Andrew and Caroline as a

validation of my commitment to them through the research journey. This merging of the personal with the professional is an important finding from the research team journey as Andrew describes.

Andrew: Going out of the research we are actually friends.

(Comment from transcription of video recording joint presentation at ASID Conference, Brisbane 2010)

This section has alluded to the requirement for researchers without disability to enter into perhaps a more personal relationship with young people with learning disability through their involvement as co-researchers.

Utilising the initial period of training

Andrew: Research is about finding out about something when you listen to people and they talk [pause] you listen yes and find out what they want to make things better.

(Extract from transcription audio recording team meeting 18/02/09 14:12)

Andrew in his comments above demonstrates a good understanding of our research aims and process. He demonstrates clarity in what we were trying to do. It also provides a powerful learning experience for me in never to make assumptions concerning their capacity and capability to co-conduct research. Andrew and Caroline always rose to each and every challenge we encountered, both professionally as researchers and personally in our support for each other.

The initial 6 week period of training (30 hours) on the nature of research, its language, aims and methods was a crucial element in laying the foundations for how we would work as a research team. It allowed for the establishment of basic knowledge and use of research terminology but crucially to further our relationship in the move from student/teacher to young adult/teacher to co-researchers to professionals and friends. Each training session lasted approximately two and a half hours, with two a week for the initial 6 week period. Some sessions were shorter and some longer depending on how Andrew and Caroline and I

felt. It was important to acknowledge that we all had different levels of concentration and that many factors impacted depending on what else was happening in our lives during those weeks. An agenda for each session defined the work that had to be completed each session but we usually came to consensus when we'd had enough. This was a further opportunity to begin to understand our individual strengths and areas for development or support and informed the roles and responsibilities that are discussed in the next section. It also provided valuable time to talk about what we were trying to find out, how we would proceed and the most suitable method. I took the lead role during this early stage and drove the process. However, as the research process continued Andrew and Caroline soon began to take more control and make demands of me with their enthusiasm for the project. I was taken by surprise at their personal commitment and motivation even at this early stage as noted in my research log:

Andrew and Caroline showed real commitment and understanding today. I am amazed with what they know and keep being surprised. Shame on me! I have to be careful not to let them down. Time is going to be a BIG factor!!

(Colin research log entry – iPhone notes, 05/04/09)

A shared responsibility

Roles and responsibilities: A desire for responsibility

There is no doubt that Andrew and Caroline saw me as taking the leading role in the research project as defined by the Health Research Council research contract (named as lead investigator), but also as they articulated “*because you are doing a PhD*” (Caroline transcription of audio recording team meeting 18/02/09 14:56). They clearly saw me as having some expertise. Over the course of the research project and beyond the power dynamic has equalised as they realised their expertise. I retained the lead role in terms of organisational matters. Responsibilities to the funding body remained with me to coordinate and monitor the process while ensuring Andrew and Caroline were as fully involved as possible. As an example the Health Research Council had described me in the contract as the principal investigator but equally important had acknowledged Andrew and Caroline as co-investigators. The contract required reporting on progress 6 monthly and although it was my

responsibility to submit the report as lead investigator, we discussed our progress together at team meetings. Andrew and Caroline recognised this acknowledgement of their status.

Our roles and responsibilities within the research project evolved and changed over time. As highlighted in the work of Lewis et al. (2008), Perry and Felce (2004) and Mactavish, Mahon and Lutifiyya (2000) we embarked on an exploration of our strengths and areas for development during the initial period of training. From this exploration we were able to allocate some specific roles to each of us that recognised and utilised the individual expertise and knowledge that each of us brought to the team. These roles changed mostly in relation to Andrew and Caroline's growing understanding and expertise with the research process and their active desire and demand for more responsibility.

With this in mind I needed to deal with the potential for being positioned as the "expert." There was no doubt this was a perception that Andrew and Caroline held from our earlier relationship in the teacher/student dyad. I attempted to equalise this power dynamic by making it clear that I could bring some experience and expertise on research methods such as data collection and analysis, organising and maintaining data and the use of more technical or academic language in research reports or papers. However, I stressed to Andrew and Caroline that they had expert knowledge through their lived experience that I could never have. Promoting Andrew and Caroline's status was achieved through leadership roles in team meetings, focus groups and presentations to groups of professionals and at conferences.

Andrew and Caroline as experts

Andrew and Caroline are proficient with the use of sign language and were able to use the symbol writing computer programme, *Writing with Symbols*. This knowledge and skill proved useful when designing the full range of accessible documents required for the research (see for example appendix 1). Many of the documents required the combination of words, symbols and pictures. Andrew and Caroline had spent many years at school exposed to a range of accessible computer programmes. This enabled them to incorporate combinations of plain language, symbols and photos in the design of the data collection instruments. They knew how to use the computer software to help create these documents

and importantly, advised on what they considered appropriate words, symbols and photos to convey the right meaning to young people with learning disability.

We worked collaboratively on all the forms and documents but the reality was that I also took this work home and worked on the fine tuning, particularly spelling, grammar and lay-out. Again what was important about this acknowledgement is that final drafts were considered and agreed by all three of us. Through this process Andrew and Caroline's contribution enabled them to take more control of the process and utilise their lived experience in the design of the data collection instruments.

It is accepted that issues concerning bias, responsiveness and acquiescence in people with learning disability provide particular challenges in the data collection process (Lewis & Porter, 2004; Perry & Felce, 2004). Andrew and Caroline enhanced the process of data collection and analysis because of their lived experience and shared identity with the research participants.

Seizing the responsibility

Through a number of practical activities during the training period and in the ongoing team meetings we began to explore and identify our strengths and also where we needed support. These practical activities took the form of role-play, basic team building and problem solving as well as taking it in turns to lead our team meetings and discussing and presenting each other's strengths. Caroline, through those early weeks and months, demonstrated her willingness and ability to take on basic administration tasks within the team which she maintained through the period of the study.

Caroline: *Right I will do the agenda for the next team meeting ok?*

Colin: *Yes that's fine use the notes you've done today.*

(Extract from transcription audio recording team meeting 18/02/09 11:46)

She would word process the team meeting agendas and print them out. She would produce plain language minutes of our team meetings from the notes we made on the whiteboard and then she would email them out to us. Assigning specific tasks to each other began to create an

environment where Andrew and Caroline could take responsibility and therefore begin to share control over the research process. They actively sought responsibility in this way. The use of information and communication technology in particular, emails and texting provided a powerful conduit for communicating their growing control and co-leadership role in the research process. This can be seen in the emails Caroline sent below:

Hi colin is Sunday happening if it is what time.....

(Email sent: Thursday, 13th August, 2009 12:24:51)

Hi colin what time do you want to meet on friday for team meeting.

(Email sent: Sunday, 13th September; 2009 16:49:55)

Caroline initiated these emails which demonstrated a willingness to take control and responsibility for the research team process.

Do u wnt to meet next week ready 4 next friday nite at upp club. But u have bare with me cos i have lost my voice caroline.

(Text sent 25/11/2010 7:02pm)

In this text Caroline was referring to our focus group meeting with the young adults at the Upp Club. She was suggesting we meet to prepare for the focus group the week of the focus group.

Hi colin do u know the dates 4 wellington caroline cn u ring me later when u r free.

(Text sent 25/01/2011 1:44pm)

Caroline's use of "textese" is typical of how most young people without disability have a particular way of scripting and spelling words in text messages.

Caroline is naturally confident, always has a view and likes to know what is expected of her. Her natural desire to be organised was utilised by the team. Andrew's strengths and capabilities came to the fore when conducting the focus group interviews or meeting people

and presenting at conferences. He has a natural ability to put people at ease through his positive, humorous, outgoing and friendly personality.

As the data collection phase unfolded our roles changed through the experience of running the focus groups. Andrew and Caroline co-conducted all the focus groups with me. We all tended to take a turn with introducing and outlining the sessions with Andrew asking the warm-up question. We had an order for who was asking each research and probe question. I found that our ability to create a relaxed but focused environment for the focus groups varied. Andrew and I were generally more successful by the nature of our personality (Perry and Felce, 2004). Slowly over the course of the focus groups Andrew and Caroline became more effective with their general presentation of questions and crucially asking the probe questions to obtain rich data. This did require significant time in rehearsal but there was no substitute for ongoing practice. It reinforced my belief that Andrew and Caroline through their co-leadership role and immersion in the research process became more skilled at data collection and analysis.

From the first to third student focus group Andrew and Caroline became more efficient and in subsequent focus groups with the young adult's group their skills improved further, as did mine. After the first student focus group I was really aware of how I was too dominant. My experience with data collection from previous research compelled me to ask follow-up probe questions to tease out deeper meaning from participant responses. Andrew and Caroline did not have this experience base to draw on and it made me conscious that eliciting rich data required me to take a more dominant role than I perhaps wanted. However, by the second of the young adult focus groups, Caroline particularly, was beginning to follow up on a participant's comment to ensure meaning was clear. An example of this was in her use of repetition as a strategy that she had probably learnt from me in earlier focus groups. Caroline would repeat the participant's comment to check on accuracy and meaning of response to validate their comment with them.

In the next extract from the transcription of the second student focus group Andrew is able to illicit richer data and greater understanding through his probe question. It demonstrated his growing confidence and expert role in the data collection process.

Caroline: So the next question is "what do you want to do when you leave school?"

Pete: *I'm gonna get a job if I can don't know whether I will get one though.*

Andrew: *Why do you think that?*

Pete: *cos its hard my mum says so.*

(Extract from second student focus group 26/06/09)

Ongoing commitment

Like any research team we had to balance the requirements of the project with many other commitments. It was no different for Andrew, Caroline and I as extracts from the ASID conference transcription highlights.

Me and Andrew we are really busy people....I have to work around Polytech for a lot of times.

(transcription joint presentation at 45th ASID Conference, Brisbane 2010).

Caroline's comments were related to the two year Work Skills course she undertook after she left school at the local tertiary institution and was demanding of her time. Andrew also alluded to the time commitment.

Colin, he takes us home after a long day of meetings.

(transcription joint presentation at 45th ASID Conference, Brisbane 2010) .

Andrew and Caroline had differing levels of commitment to the time required for the research and this reflected their natural difference in energy levels but also their personalities. Andrew naturally tired more quickly than Caroline.

In the research diary entry below (Figure 11) Caroline shows her growing awareness of the research process and the requirement to write reports and work within the guidelines and protocols we wrote for working together in a research team. It also reinforces the personal and professional dynamic of our relationship as an enjoyable venture as when she says "*and we do have the odd laugh.*"

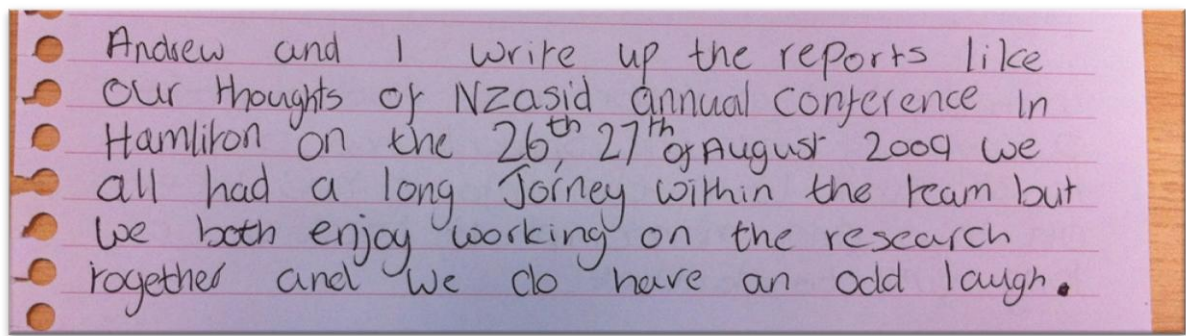


Figure 11: Reflective account from Caroline's research diary

Time matters

As highlighted by Condor, Milner and Mirfin-Veitch (2011) in their New Zealand PAR research article time was a critical factor in researching with people with learning disability. I knew initially I would be taking responsibility for ensuring adequate time was allocated and how that time would be best used. An important finding from our experiences through the research journey was that no matter how much time you allocated there were always pressures on it.

Caroline: Yes it takes time to know what I am doing and slower you know.

(Extract from transcription of audio recording team meeting 18/02/09 14:12)

One important realisation that Caroline articulates in her comments above was the ongoing pace and length of the research process and that it would be slower (Burke et al., 2003). Early on I had to constantly readjust what work we would get through but my experience as a teacher helped me to deal with my frustrations. The requirement for honesty concerning my frustration at times is important for researchers without disability to accept. As a result on more than one occasion I finished off a research instrument we had been working on together because there simply was no time to organise another meeting in order to complete it. This was usually to complete the design of a focus group participant letter or information sheet or protocol sheet for each session. However, I ensured that I showed the finished product to Andrew and Caroline so they could comment on it before we used it. It is critical to find the extra time required to ensure the young people with learning disability are fully involved at

all stages. There are obvious tensions when studies might be restricted by demands from funding bodies that compromise resourcing and time.

I was also concerned that the pace of our work would compromise the quality of the research design, data collection and analysis. This was because of the need to explore, explain and discover together. Each stage from data collection, analysis, findings and reporting required more time in practical inquiry activities and rehearsal. There needs to be recognition that gaining access to participants, developing accessible information and forms, explaining the aims and nature of the research and ongoing consent and assent will take considerably more time than other forms of research. Ensuring that Andrew and Caroline were fully involved in this process demanded considerably more time to generate robust, accessible data collection tools (Lewis & Porter, 2004). Time or the lack of it was something we battled all the way through the study. However, there was no doubt in my mind that the more Andrew and Caroline were involved in all aspects of the research process the more robust the data collection and analysis.

One way of mitigating the time factor was our use of information and communication technology (ICT). As a result we became more efficient with our time management and this improved as the study progressed. We relied more and more on email and texting to organise team meetings and pass logistical information on the research between us. It also meant we were in effect working outside of the usual workday hours. Andrew, Caroline and my use of ICT and particularly mobile phone telephony and the internet, was enhanced over the course of the project with all of us becoming more proficient. An example of what I learnt from Andrew and Caroline was how to construct texts quicker by using textese. Andrew and Caroline maturing during the mobile and email technology era naturally supported their familiarity and capability. In addition I learnt to use the notes application on my iPhone for research diary entries. I also learnt to download our complete text and email trails over a nearly three year period to use as valuable data for analysis. Caroline completed a computer course at the local polytech during this time in addition to her two year Workskills course which further enhanced her skills.

Sharing control through technology

Technology was a significant factor in how we communicated.

Colin: *So how do we communicate?*

Caroline: *Text, email, seeing each other, telephone.*

(transcription extract joint presentation at 45th ASID Conference, Brisbane 2010).

Andrew and Caroline have their own mobile phones and access to the internet for email. They got their mobile phones during their last year at school. As the comments above describe, we use technology on a regular basis to communicate and it greatly enhanced the research team process. The verbatim comments below taken from email correspondence with Caroline illustrate how we were able to organise team meetings, disseminate agenda's/minutes and resolve logistical matters.

Can we meet at the university with Missy on Friday at 1.30pm? That would be great.

Cheers, Colin

(Email sent: Tuesday, 1 Sep 2009 22:14:32)

Hi colin sounds great i can bus but is on the other side of the unniversity on arts road so either you pick me up on the way or i could meet you at nagio marsh theature its your choice. caroline

(Email sent: Wednesday, 2 September, 2009 11:19:20)

Caroline's email above shows the reciprocity in our relationship where she is comfortable enough to direct me with the arrangements for meeting up with her at the university. We used technology on a regular basis to communicate and it greatly enhanced the research team approach. We were able to organise team meetings, disseminate agendas/minutes and resolve logistical matters using text, phone calls and email. The outcome through this process has been the gradual shift in responsibility for making the first contact from me to a shared one. The research dialogue has often been initiated by them with a phone call, text or email to set-

up the next team meeting. This is illustrated in a research log entry I made utilising the notes programme on my iPhone.

18/08/10: Andrew rang this evening off his own volition. Asked when we having our next meeting. I mentioned about booking flights for ASID conference in Brisbane. Said I have put in our application for funding for registration and accommodation costs. Andrew and Caroline and parents to discuss how they will contribute cost of flights-will it be part paid from their research assistant salary? They will decide.

(Colin research log entry – iPhone notes 18/08/10)

The email from Caroline below demonstrated how she was confident enough in her status within the team to tell me that she could not make a particular meeting because she was otherwise engaged. This was early on in the research study. The email message and content are presented in full.

*From: caroline quick <(withheld)>
To: colin gladstone <gladbrick@yahoo.co.uk>
Sent: Thursday, 30 July, 2009 8:44:42
Subject: RE: research stuff- caroline*

hi colin i cant do it tonight because i have another meeting at 4.30 so can we do it tomorrow or next week. sorry andrew texted you to tell you that i cant make it for today caroline

(Email sent: Thursday, 30 July, 2009, 8:44:42)

Caroline reinforces her position when she says that Andrew had already informed me by text that she could not make the meeting.

In the next email presented Caroline shows firmness and authority in informing me that she had already told me about starting to write her speech for a conference presentation. At the time I had been gently pressing her for this. It perhaps shows the fine line required when working in any collaborative team approach and is no different when working with young people with learning disability. In the extract she reinforces her growing authority in not only telling me she had started the speech but also in wanting more to do. Her use of direct language as with “*I already told you*” illustrates her status within the research team.

*From: caroline quick <(withheld)>
To: colin gladstone <gladbrick@yahoo.co.uk>
Sent: Wednesday, 22 July, 2009 11:15:58
Subject: RE: research stuff- caroline*

hi colin i already told you that i have started the speech for hamilton is there anything else for me to do caroline.

(Email sent: Wednesday, 22 July, 2009 11:15:58)

These examples from emails demonstrate their growing status, sense of importance and value within the research team.

Mentor and supervisor

In any research there are inherent dangers with regard to the vulnerability of participants. In this project the dangers are more overt through the involvement of young people with learning disability as not only participants but also when they act as co-researchers within a research team. Andrew and Caroline's active role as co-researchers in the research design and delivery of the project helped to minimise this risk for the participants. However, in order to minimise the risk for Andrew and Caroline we discussed very early on at a team meeting how we needed to respect each other's views and vulnerability. As well as agreeing on a team protocol for working together we discussed it in terms of "supporting," "listening" and "having someone to talk to, if things got difficult." I explained about my doctoral supervisor acting in a similar role for my doctoral studies and they decided that it would be appropriate to have a third party to fulfil this role for them. We discussed different people we might approach and Andrew and Caroline decided on someone we all knew well, who had been the project manager for Wayne Francis Charitable Trust project that we had all been involved with and who had a lived experience of disability. We arranged an initial meeting where we drew up a protocol for how they would be able to have support and contact with the mentor, if and when required, through the project.

Practical matters

There was much give and take in our relationship through the research study inherent in working as a research team. Every stage of the research process as earlier described in this chapter had to be mapped out as with what at first glance might be viewed as the simple logistical matter of organising a team meeting. In the early stages of the study Andrew and Caroline were not yet proficient at using public transport and yet it was something they wanted to practice and the opportunity to bus to a team meeting was useful. We generally met at the end of a day mostly after 4pm when Caroline had finished her tertiary course, Andrew had finished at his vocational day centre and I didn't have a meeting after school. Andrew and Caroline would bus to the meeting venue at the university from starting from different locations. Usually the journey involved two bus trips for them and a short car journey for me. Initially we worked out the route together using bus timetables and involved their parents so we were all clear about what was happening. Andrew and Caroline were able to keep in touch with each other and me through texting during the journey. Their enthusiasm for learning new routes provided the impetus to quickly become fairly proficient with bus travel. They would mostly bus to the exchange (bus depot) and would then travel together for the second bus journey to the university. I would then usually give them a lift home after the meeting. The fact that Andrew and Caroline learnt to travel on a number of different routes in the city was an important practical outcome from our collaboration. In addition through presentations at conferences both nationally and internationally they have become more assured and self-determined in organising their time and arrangements. They have used many forms of transport, including planes, trains and automobiles. Since the end of the research project Caroline has travelled by herself on domestic flights to attend seminars and conferences.

Team meetings

The regular team meeting format was a useful way of ensuring that Andrew and Caroline were prominent in the research process. We met on a regular basis after the initial period of training usually once a fortnight for two to three hours depending on how things went. As with the initial training our focus varied and we had to be sympathetic to it and work accordingly. The earthquakes disrupted our meetings for an extended period of months and we had to work around this with different venues and timings.

Conference presenting

I had attended a number of conferences and seminars through my research based Masters Degree in the United Kingdom and had attended a DSE conference for the first time at Syracuse University in the United States in 2009. This was shortly after embarking on my doctoral studies and suggested by my supervisor. My attendance at this my first DSE conference brought home to me that while it was fairly common for academics and educationalists with disability to present, young people with learning disability were largely absent from the conference platform. I was determined to challenge this and in discussions at our early team meetings Andrew and Caroline said they were very keen to present and experience the conference platform as shown in Caroline's research diary entry.

The conference platform was a key vehicle for Andrew and Caroline to show themselves as capable, confident researchers. An accepted aspect of any research study is the dissemination of findings. I wanted to ensure Andrew, Caroline and I seized opportunities to present to different audiences through the conference and other presentation platforms. Andrew and Caroline had experienced an early taste of presenting when they were chosen to give a speech at the launch of the LSTS in August 2009 to a large audience including the then Associate Minister for Education, the Honourable Heather Roy. They had presented for a few minutes from a prepared speech that we had worked on collaboratively but closely resembled what they wanted to say regarding transition. Afterwards people were coming up and congratulating them on their speech including the minister and MoE representatives and the chief executive of the chamber of commerce. At the supper later in the evening I could sense their growing confidence and status as a result. This experience had fuelled their growing realisation that people wanted to hear what they had to say. The fact that people valued their lived experience was an important realisation for Andrew and Caroline. This realisation for young people with learning disability can be obtained through the experience of having the opportunities to present in the "expert" role.

Gaining validity as researchers

I feel that I am an independent and confident young lady because I love my job as an research assistant. It give me the experience and confident because I stand at

the front of an audience and I talk about our research. And after we spoke to the audience they all clap and I stand back and I smile thinking wow what an achievement that I have achieved.

(Caroline reflective account word processed from her research diary 12/10/11)

Caroline's narrative on what it means to be a researcher provides a persuasive argument for research that empowers and hands control to young people with learning disability. Caroline and Andrew's growing status through the research process was evident in a number of ways.

Recognition through working onsite at the university

In promoting the status of Andrew and Caroline as researchers we held meetings in an office at the university. Andrew and Caroline had their own workstation. However, due to the devastating earthquakes in Christchurch from 2010 and 2011 we conducted our team meetings in a variety of environments and venues from coffee shop, my home, their home as well as different places on the university campus. Importantly, they remarked that meeting at the university gave them a greater sense of importance.

Caroline: I like it at uni I feel important with all the other students around.

(transcription of audio recording team meeting 14/10/10 16:42)

Recognition through university contracts as research assistants

Andrew and Caroline's status was also enhanced by having a contract with the university as salaried research assistants. This was something they were very keen to have and they considered it was an acknowledgement of their status as researchers. It also confirmed their status and relationship with the university. Both Andrew and Caroline were very proud to have signed this contract and to be paid for their work at the going rate for research assistants. However, while the university were happy to award Andrew and Caroline a research assistant contract the funding for their salary came from the Health Research Council PhD Scholarship I was awarded and not directly from the university itself. It would have been interesting to test if the university would have provided their contracts if they were paying?

Recognition as researchers from the “experts”

I use an email from a respected academic to illustrate further the growing status that Andrew and Caroline had as credible researchers. The email was received after a presentation we did at the National ASID conference in Hamilton 2009.

From: (withheld) >

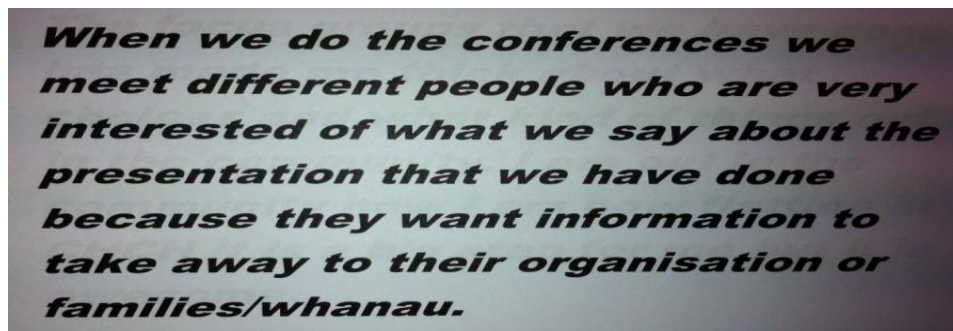
To: “gladbrick@yahoo.co.uk” <gladbrick@yahoo.co.uk Sent: Friday, 28 August, 2009 9:43:23

Hi Caroline, Andrew, and Colin, I chaired the workshop you presented. I would like to extend my thanks at your participation in the conference and to let you know what a privilege it was to chair this session and to learn about your exciting research. I hope that we will be able to follow its development and wish you all the best with this important work. Andrew and Caroline you are excellent presenters and provided a huge amount of leadership and gave others the confidence to try.

Many thanks (name withheld)

(Email sent: Friday 28th August, 2009 9:43:23)

Recognition through presenting at conferences



When we do the conferences we meet different people who are very interested of what we say about the presentation that we have done because they want information to take away to their organisation or families/whanau.

Figure 121: Reflective account from Caroline’s research diary

Caroline’s diary entry (Figure 12) demonstrates her understanding of the value of conference presenting. She describes the networking opportunities conferences provide and their value for providing information that the audience can take away, particularly parents.

In seeking international opportunities for Andrew, Caroline and I to co-present we targeted the Australasian Society for Intellectual Disability (ASID) Conference in Brisbane, Australia during 2010. This conference fulfilled two criteria for us: firstly, it was a conference specific to people with learning disability and secondly, it was international. Andrew, Caroline and I spent two team meetings writing a submission for the conference which was accepted amid great excitement from all three of us. My research diary logs how excited Andrew and Caroline were at the prospect of travelling abroad to attend the conference with the flights and staying in a hotel. These opportunities were important to them particularly as they were experiencing them without their parents. However, the cost of attending was going to be a challenge and meant we had to organise international travel, accommodation and conference fees which amounted to in excess of \$5,000. The financial cost for presenting raises important issues about conference fees for people with learning disability who are overwhelmingly on benefits. There are often reduced rates offered but the cost is still prohibitive when accommodation and travel costs are considered. My professional conversations with people over the years lead me to believe it stops many young people with learning disability from presenting or attending. Another reason might be the support and time required to undertake funding applications and raising funds. Equally, the time required to support the young people to attend the conference. We spent many hours writing our proposals and papers for the conferences. In the event we used \$2500 from the HRC scholarship and successfully applied for reduced costs to the ASID conference committee who waived registration fees for Andrew and Caroline at \$600 each. I contributed about \$800 personally and we were able to cover costs with Andrew and Caroline contributing \$250 each. Andrew and Caroline said they felt it important to contribute financially described by Andrew as “we pay our share you know.” This determination to take responsibility for the research costs resists typical images of people with learning disability as passive recipients of welfare.

Our attendance at the 45th ASID conference in Brisbane was an opportunity to present our research to an international audience. It was also an opportunity to challenge deficit beliefs concerning how young people with learning disability can be meaningfully involved as leaders in the research process about issues concerning their lives. Conference presentations by young people with learning disability are still relatively few nationally and internationally.

Our experiences during the ASID conference were overwhelmingly positive with several hundred delegates attending. The opportunity for all three of us to meet and be seen as a research team was important in sending a message concerning the relational possibilities in research collaborations. The large majority of people attending were people without disability representing a wide variety of government and non government agencies and organisations, parents and professionals. Andrew and Caroline seized the opportunity to enter into discussions with many of the delegates over the duration of the conference and my belief is each interaction supported their own growing awareness of their value and status within the research process. More significantly it saw my and the other people's awareness grow for what was possible. Andrew and Caroline were keen to use the opportunity to enjoy the benefits of attending a conference outside of the official programme. We went out with other people to enjoy meals and drinks as well as sightseeing. We all enjoyed the personal and professional aspects of the conference trip together.

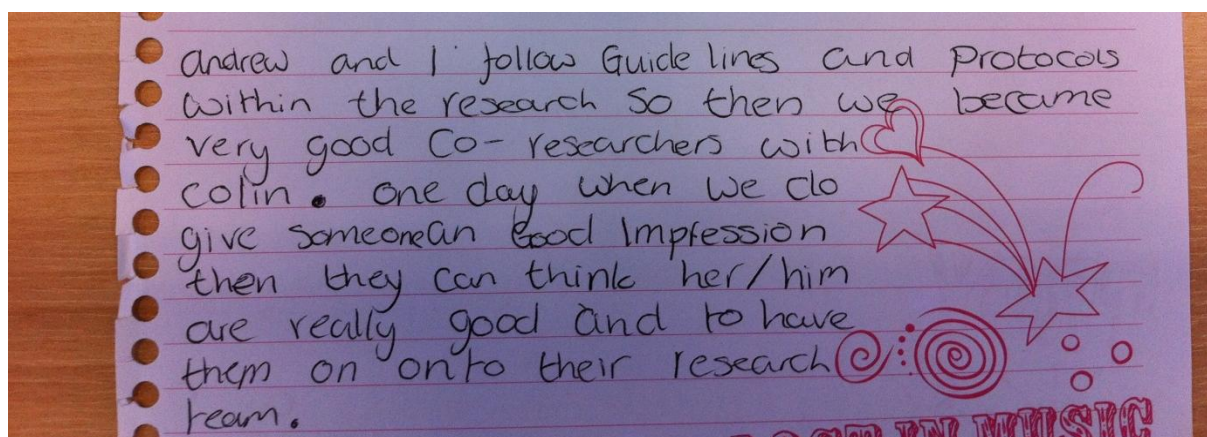


Figure 13: Reflective account from Caroline's research diary

Caroline understands that demonstrating her capability as a researcher in our project might lead to recognition by others in the field and the opportunity to work on other research (Figure 13).

Recognition from their peers

There was no doubt that the research participants, both students and young adults, recognised the significance of Andrew and Caroline co-facilitating the focus groups. Andrew and Caroline's status among their peers was enhanced through the research process. The

participants experiencing Andrew and Caroline in a leadership role within the focus group sessions asking the questions and co-directing proceedings made an impact on how they responded. There was a tangible respect best exemplified by how the young people responded to Andrew and Caroline.

The research process adopted was deliberately targeted at enhancing the status of Andrew and Caroline as co-researchers and with constructing a space for their narratives, but also for other young people with learning disability within disability research. Andrew and Caroline have stated their intention to “do more research.” This is more than about allowing a space for the research participants to tell “their stories.” it is also about how Andrew and Caroline’s active involvement and contribution as co-researchers influenced the telling and how they then co-interpreted the findings.

What I have learnt from Andrew and Caroline

Reciprocity and trustworthiness

Through the research journey I have learnt more about my own inadequacies and biases than I ever thought imaginable. I still in my continuing relationship with Andrew and Caroline have the opportunity, through their willingness to share a part of their lives with me, to learn and grow as a human being first and then as a friend, co-researcher and teacher. A point of difference in this research is that it naturally will test the regimes of trustworthiness and reciprocity (Harrison et al., 2001). It takes risks in exploring the interrelatedness of trustworthiness and reciprocity as it considers the relational dimension of Andrew, Caroline and I as co-researchers and not as is most common in learning disability research the relationships between researcher and participant. If we define reciprocity as “give and take” (Harrison et al., 2001 p. 325) then what do we give and what do we take from each other? I use trustworthiness to mean the way that I ensure my co-researchers recognise my empathy, credibility and validity to conduct research with them about their lives (Harrison et al., 2001). We are co-researchers from the early stages of research. We also go beyond the researcher/participant boundaries to explore how our personal and professional lives are entwined through the research process inherent in working collaboratively as co-researchers within DSE and learning disability research over a long period of time.

There were implications both during and after the research study was completed that put a responsibility on me to ensure that Andrew and Caroline's future life goals post project are not in any way compromised and if desired they can move on to involvement in other research endeavours. Subsequently this has proved to be the case with Caroline's involvement in the joint government department initiative *Enabling Good Lives* work.

Andrew: *I know I can trust you*

Colin: *How do you know?*

Andrew: *Because you spend time with me ... you let me do things*

(transcription of audio recording team meeting 18/03/10 17:28).

The extract above from a conversation in a team meeting illustrates two important elements in this research that positively influenced its outcome; trust and time. The recognition by Andrew that by spending time with him and handing control to him he can experience trust in another person is important in any human interaction. By promoting opportunities for reciprocity in our interactions, Andrew and Caroline took responsibility (Lather, 1991). What I gained from Andrew and Caroline fuelled my obligation to their desires not only from the research process but in their lives generally. The trustworthiness of the research journey through this thesis as valid and credible must be judged in part by whether it moves Andrew and Caroline's lives forward in ways they acknowledge as worthy. In addition we had a collective obligation to our research participants to tell their story in a way that promoted their lives and sought to improve the transition process from school for students and young adults with learning disability. Recommendations for the transition process are provided at the end of Chapter 8.

Jobling, Moni and Nolan (2000) proposed in their study individuals with learning disability may not fully understand the emotional aspects involved in the development of relationships (p. 236). My experiences over the years in my relationship with Andrew and Caroline show me it is not only individuals labelled with learning disability who may not fully understand the emotional aspects but all people. Emotions are certainly not only the domain of people without disability as Andrew and Caroline demonstrated on many occasions. Our research demonstrated that this was not so much related to whether someone was labelled with

learning disability or not, but by the same factors as anyone else i.e. context, life experience, intra-personal attributes and the environment we live in day to day. Our relationship was strengthened by its ethic of care (Noddings, 1995) and its ethic of hope (Van Hove et al., 2012).

What after? The ending of participatory research

I was mindful of the “ending of participatory research” as described by such researchers as Booth (1998), Goodley (1999) and Northway (2008). They reinforce the view that research is a process and emphasise the importance of the “what after” the research project as one of many themes to address. Our commitment was demonstrated in the recognition that it was our friendship that enhanced our professional relationship. We all agreed that the friendship was a crucial aspect of our relationship and that it supported the reciprocal, agential nature of our interactions as human beings. We spent time together socially, going for a drink and dinner. We often went to each other’s houses socially and we all valued having that personal connection with each of our families. This friendship and emotional connection was illustrated when my father died and Caroline and Andrew offered emotional support.

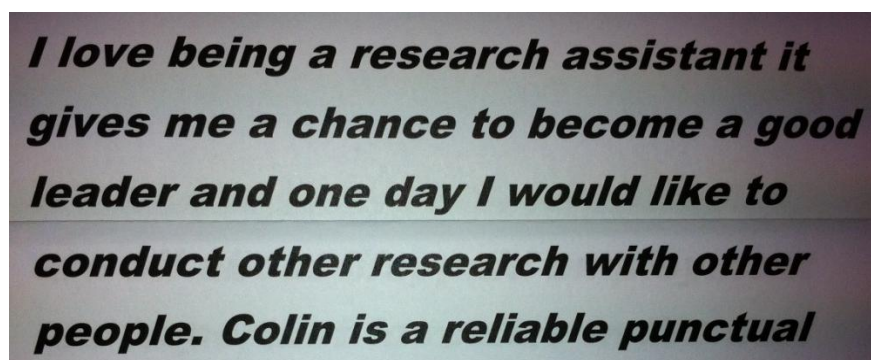
Hi colin i am so sorry that your dad has died if there is anything that i can do let me know colin take care of yourself ok. I have spoken to jill and she is fine and the boys too. Colin listen to me everything will be fine trust me. Me and Andrew will always be there for you and jill and the boys. See you when you get back take care caroline.

(Email sent: 01112009 23:34:30).

The feeling of care conveyed in the email from Caroline and the way she constructed it and the language used was a shared emotional experience and illustrated the strength and depth of compassion required in the relational dimension that positions our personal and collective journey. It speaks volumes about Caroline’s empathy and understanding of the emotional state at my loss. As with an ethic of care she was willing to look into my life and my emotional state and offer support. This emotional aspect in the research process as reflected in feminist research plays an important part in how we relate to each other (Noddings, 1995).

Carlson (2010) asks an important question in relation to learning disability research: “Who is the expert?” Knox et al. (2000) describe “working with the expert.” By assuming the role of expert what does this assume about the role played by the expert? What authority does someone have to assume the role of expert and what responsibilities does it bring? Is there a measure of autonomy when assuming moral authority? My position aligns with Carlson in moving beyond an individualistic model of autonomy. This allows us to move away from moral authority being within an autonomous individual to one where it is situated within relationships. Carlson also discusses epistemic authority and the dangers of assuming knowledge about the kind of life those labelled as intellectually impaired young people want. I cannot and never will be able to assume epistemic authority with regard to knowledge claims concerning the young people with learning disability in this study. However, I can, as Kittay (2010) articulates, ensure that I assume “epistemic responsibility and modesty” in my relationship with Andrew and Caroline. Additionally, the young people in our study are not representative of all people labelled with learning disability as a heterogeneous group.

Silvers and Francis (2009) view autonomy as “relational.” I was compelled to examine my relationship and self-motivations to the process with Andrew and Caroline through this research project. I had also to deal with the “ending” of this piece of research (Northway, 2000) and how it impacted Andrew and Caroline’s future life goals and pathways, and, if desired, future involvement in research.



I love being a research assistant it gives me a chance to become a good leader and one day I would like to conduct other research with other people. Colin is a reliable punctual

Figure 14: Reflective account from Caroline’s research diary

Caroline’s wish to be a leader and conduct research with other people (Figure 14) exemplifies how she has grown as a person and researcher through this collaborative journey. She is able to assess my performance as a co-researcher when she describes me as “*reliable punctual.*”

She has gone on to be the president of the local region's People First organisation demonstrating her capability for leadership. She has also participated, as mentioned in other research, most recently as national committee member of *Enabling God Lives*. Her recognition of this is shown in her comment below.

I am asked to speak now without you Colin

(Extract from transcription audio recording team meeting 22.09.2011 09:43)

There are real challenges in establishing effective, enduring research partnerships between young people with learning disability and researchers without disability. However, I firmly believe that only when I challenged my pre-conceptions about the meaningful involvement of people with learning disability as valid researchers and not just as participants or to check the validity or credibility of findings did I move my thinking forward. Only then did I begin to unpack my true motivations for conducting this participatory research. My realisation was that through the research process both the professional and the personal are unavoidably entwined when working with students and young adults with learning disability. How the non-disabled researcher addresses this relationship will define the true success of any endeavour and demands a long-term commitment, an ethic of care and pedagogy of listening (Macartney, 2010) and hope (Van Hove et al., 2012). If anything this research project so far has shown me that "life after the research" is more important than "life with the research." As we continue beyond this research project Andrew, Caroline and I have offered some insight to their meaningful involvement in research. We are co-constructing forms of knowledge and research agendas. Only through the journey can we discover this knowledge.

Caroline has completed her tertiary course has some part-time paid employment but is looking for more. She has become an advocate and president of the People First regional branch and is involved in other project work. Andrew continues to attend a local vocational service and does unpaid voluntary work. He has recently moved from the family home into a flatting situation and is still looking for paid employment.

Crafting identities

The personal and the professional

As previously described Andrew, Caroline and I had known each other since 2008 in the student/teacher relationship at school. We were thus experiencing the transition process from different positions of power, I as their transition teacher and they as students transitioning from school to post-school life. The requirement by teachers (often for their protection) to maintain a professional distance with their students is wrapped up in discourses of professional power and control.

Traditionally, being in a professional working relationship often means the personal or friendship is taken out of the relationship. Andrew and Caroline were aware of this very early on and were clear about how they saw the dynamic as equally important. This demonstrated their growing professionalism. Andrew articulated with the following comment from a team meeting:

Andrew: When it's professional it's time to work.

(Transcription of audio recording team meeting 14/03/09 16:35)

There is no doubt this was made easier by all three of us acknowledging the requirement for focus and concentration during work times. Equally, we were all able to enjoy our time together whether working or socialising away from the research. The physical environment played a part in supporting the professional environment typified by when we were working in the university office or at the venue for the focus groups. The devastating earthquakes in Christchurch did force us to use other venues for our team meetings but we were all able to respond professionally despite the ongoing nature of the earthquake and aftershocks having a significant emotional impact.

The personal and professional relationship matter

Colin: So come on then what is our relationship?

Caroline: *When we are down to work we are professional, because we talk about professional things when we are working together, but going out of the work we are actually friends.*

Colin: *That's very important so there's a distinction, there's professional and there's friendship?*

Andrew and Caroline (together): *Yes, yes!*

Colin: *Which do you like, which do you value more?*

Caroline: *Both!*

(transcription joint presentation at 45th ASID Conference, Brisbane 2010)

The above passage signals how Andrew and Caroline viewed the relationship as being both on a personal and professional level. We had known each other for three years at the time this comment was made and it demonstrated how our relationship had evolved from the teacher/student dyad to being both a professional one and a developing friendship. They valued the friendship that we have outside of our professional work and see both as equally important. This has serious implications for me as a co-researcher without disability who must be clear about the possible form and nature of the relationships that might develop. I felt an obligation to consider very carefully how my relationship with Andrew and Caroline might develop outside the research study. I felt an acute sense of obligation for the other that must go beyond the typical relationships that defined students and young adults' interactions with people without disability as researchers or otherwise. The reality being that we are now friends outside of any professional work we have. That it went beyond an obligation to the other is important and requires those involved to have an emotional investment. This is defined as with any friendship and can be manifested by going out socially and spending time in each other's company beyond the professional obligations. This is not to say that when researching within the DSE field it is not possible to conduct effective research without entering into a relationship that demands a considerable personal and emotional investment on the part of both parties. In our research study the nature of our relationship was defined by our own individual and collective motivations over the extended period that continues today. Change has been a part of the ever-evolving relationship and defines any search for a good life.

That I am so much older than Andrew and Caroline raises issues that also warrant careful consideration. It would be unusual for a couple in their fifties like my wife and I to be going out socially with young people in their twenties. Are there implications regarding this? These considerations are important in ensuring Andrew and Caroline are not disadvantaged in any way. Is this simply perpetuating the “adult with restrictions” status where Andrew and Caroline are not socialising with peers of their own age? Or indeed maintaining my adult status to maintain control? I was very conscious of this and talked to them about it. Their response was puzzlement and explained by them saying that age does not matter when you’re friends. The literature as highlighted earlier suggests that people with learning disability have generally restricted social networks (Forester-Jones et al., 2006; Lippold & Burns, 2009; Rosen & Burchard, 1990). I was aware to provide opportunities to expand their social networks in a positive way. Intergenerational relationships in many cultures outside the Western world value interactions where age is not a barrier.

Moving in different circles – breaking down the doors of academia

Through the research journey Andrew and Caroline have come into contact with a wide variety of people in work and social settings through attendance at conferences and speaking to different groups nationally and internationally. They have become used to meeting and mixing with a wide variety of people in a variety of social settings. Like anyone these opportunities develop our capacity for sociability and consequently how we view and position and organise ourselves in the social world. The opportunity to experience a wide variety of social settings together was important in supporting our individual and collective journey towards a good life. Through the research journey Andrew and Caroline met and demonstrated leadership with, peers with and without disability, parents, academics, teachers, researchers, government officials and ministers to name a few.

Playing with power

Andrew eloquently describes the changing power relationship in the following discussion at the ASID conference.

Colin: Has our relationship changed through the research process?

Andrew: *Yes I think it has changed because of the teacher student thing you said. You used to tell me what to do as the teacher.*

Colin: *Okay but what about now?*

Andrew: *But now we can tell him what to do!* [Andrew looks at audience laughing and audience laugh too]

(Transcription from joint presentation at 45th ASID Conference, Brisbane 2010)

Andrew's comments acknowledge the changing dynamics in our relationship and rejection of the teacher power status. He felt secure enough to resist and challenge playfully the status of the teacher to the conference audience as a deliberate strategy to exert his feelings of power and control as with "But now we can tell him what to do." Andrew uses humour in asserting his identity and considered clearly that the power dynamic had changed. It is an identity that Andrew enjoys and plays with. Much more easily identified at the time or in the video, he also used his innate humour to exemplify the caring, reciprocal nature and trust in our growing relationship. There is warmth in the interaction that allows for this form of interplay during what was potentially a daunting occasion for Andrew co-presenting in front of the conference audience. His use of humour exemplified his capability demonstrated again for example when co-facilitating the focus groups. His skill and strength of personality was able to create a relaxed atmosphere for the participants.

Carpe diem: Shifting the context to gain control

In this section I show that by shifting the context Andrew moved from being controlled and managed in one setting to seizing control in another perhaps as a result of his growing confidence. In doing so he moves from incapable to capable on the basis of context and seizing the opportunity. At the time Andrew was in a supported living situation run by a local residential service. He was in a flat with another young man although he had also been in the hostel setting. The flatting situation was for those looking for more "independent living." However, the reality for Andrew manifested itself in a set of house rules that regulated and controlled most aspects of his life. Andrew was under the influence of a service orientated regime that dictated what he was allowed to do, when and with whom. A typical example of this regime was his girlfriend not being allowed to come over to his flat for tea and not being

allowed out after a certain time in the evening (9.30 pm). Remembering he was in his early twenties at the time. My experience of the service over the years had left me with the impression that it was organised around the staff and in particular the manager. Andrew has always been someone with a well developed sense of what is right and wrong and he became very frustrated with the controlling regime. This unsatisfactory situation went on for a number of months and there were various meetings with him, his parents and the service.

During this time we had completed our research findings report (Dever, Gladstone & Quick, 2012) and had arranged to present our findings to the Minister for Disability Issues the Honourable Turiana Turia at the university. There were a number of officials from the university including the pro vice chancellor of the College of Education. We gave our presentation which was very well received by all present. In the informal discussion afterwards Andrew seized his moment with consummate timing. He casually (and deliberately) mentioned to the minister that he was having “a bit of trouble” with the manager of his group home who was making his life difficult and that it wasn’t right. A short discussion ensued with the Minister quick to acknowledge Andrew’s concerns and said she would look into it. In the days after our presentation the Minister was true to her word and her officials made contact with Andrew and his parents to investigate the matter in more detail and resolve the situation satisfactorily. Andrew had seized the opportunity to resolve a concern he had in his life and demonstrated his capability in taking a measure of control over his life. The incident brought home to me how in one context Andrew was seen as requiring close supervision and his life micro managed when in the residential setting. In another context Andrew seized the opportunity to resolve his problem through action and agency with people who wield great influence.

Chapter summary

This piece of research has got alot of poteinal and to achive of all the learning of what research is all about. We had som e ups and downs but we have stayed strong as a team to get on with each other. When Colin can’t make a team meeting he contacts us and to make a different itme, date, day when its suits us. This is mine and andrews passion and to understand what people with disability

wants to do in their life and their future. I have had people who has supported me a 100% behind me on this I had mum and Danielle (my sister), Andrew and Colin of course. Now Andrew and I are finalise our reports for us to give out information to people who are interested of what we do and say about transition. We go then present to the minister of education in Wellington.

(Extract Caroline's word-processed research diary from 22/10/2011)

Caroline's rich and insightful description of the research process and its contribution to her life goals and ambition to understand what kind of life "people with disability" want now and in the future is important and demonstrates her desire to be a leader. Andrew and Caroline have demonstrated through the research process an awareness of their capabilities as people, researchers and advocates. Andrew and Caroline actively seized opportunities to take more responsibility for and contribute to the research process. This then translates to a desire for more control over their lives and importantly to advocate for others with disability.

Our research journey has shown time and logistics to be significant factors in the success of this project as found in a study by Chapman and McNulty (2004). However, it is the realisation that obligation, care and reciprocity will overcome the myriad practical challenges. In addition it is recognising what we have in common as humans that are central to obtaining insight to the lived experiences of young people labelled with learning disability. The implications of our research study position effective relationships as central to how people with and without learning disability can find shared understandings and acceptance. Andrew and Caroline have demonstrated their capability with many of the technical aspects of research. Importantly, they understand the value of people with lived experience, co-disseminating research findings at conferences and saw it as a powerful advocacy and tool for change.

An important realisation for me through this research journey has been that shifting the context is a powerful force in the liberation of those whose lives are largely controlled and managed by deficit discourses, assumptions and mechanisms of power. I realised this with Andrew and the controlling, disciplinary experiences he had when in a residential service flattening situation and mirrored in the negative experiences of some of the research participants described in Chapters Five and 6. Andrew took the opportunity that came when presenting to the Minister and went from being controlled to seizing control.

This chapter has utilised findings from the research team's journey over an extended period to highlight the evolving, interdependent, reciprocal relationship of Andrew, Caroline and I. It has shown how the relational dimension can provide an alternative space for those who are excluded and marginalised by unequal power relations. This chapter has demonstrated through the narratives of the research team journey how unequal power relations and exclusionary policies and practices can be challenged. Challenged through trust, reciprocity and risk towards an ethical space where we are all valued for who we are.

CHAPTER 8: DISCUSSION AND CONCLUSION: “IT’S ALL ABOUT RELATIONSHIPS YOU KNOW!”

In this thesis I have sought to understand the complex social, political and cultural influences and contexts that determine how a particular group of young people labelled with learning disability successfully transition from school in their search for a good life. The structure, style and content of my thesis traced a personal and collective journey towards deeper understanding. I have deliberately framed my argument to articulate research questions and findings that have implications far beyond the technical aspects of a particular transition process. Best practice in transition planning is well researched and well established. Poor transition planning is not the problem. This study has shown that answers to how young people with learning disability can transition successfully in their search for a good life are more about values, equity of opportunity and social justice.

I have argued that the transition process for students with learning disability is defined by an exclusionary landscape resulting in a restrictive pathway that mostly leads to unrealised lives. Theirs are unrealised lives in the sense they are not likely to realise their clear goals and aspirations unless the present system changes. The implication of marginalised lives will often mean lifelong welfare consumption with little sense of belonging, value or purpose in life. In the current fluid education market environment young people with learning disability are likely to have their identities constructed by what they are not, by what they do not do and by what they cannot afford (McClimens & Hyde, 2012; Mullaney, 2001). In this way they mostly do not engage in post-secondary education that provides meaningful and fulfilling pathways. They mostly do not have paid work. They mostly do not socialise with people without disability other than family or support workers. Indeed, when you are the commodity you do not have much purchasing power. Young people with learning disability are not consumer, purchaser or producer of commodity in this education and social welfare market environment. They have become the commodity traded by the special education and disability industry. A commodity maintained by service industries with a vested interest to perpetuate themselves. I suggest solutions to this marketised proposition, that creates an exclusionary landscape, can only be relational and not individual. By this I mean that

establishing enduring relationships at all levels is critical in realising the kind of community from which all might benefit.

As a counter narrative to exclusionary discourses the voice of the young people with learning disability, together with the story of this PAR journey, has demonstrated these young people are optimistic, insightful and capable. Furthermore, they have a great deal to offer if provided the right context, understanding, support and opportunity to contribute positively and to take on responsibility. The findings from our study show that these young people have clear goals and ambition for their lives and want to actively contribute in mainstream life that they think will provide them with a greater sense of belonging. In addition, the narratives of the young people have provided a sharing of their emotional selves that allows for new identities and a unique cultural space within Bauman's liquid modern society. These narratives challenge and reject a normalised, consumptive, individualistic view of life. These new voices in authentic partnership with people without disability can contribute to social change that, in turn, provides the rhetoric of special and inclusive education policy with practical solutions. Young people with learning disability attending colleges and universities, working alongside us in paid employment and actively living among us will crucially enrich everyone's lives. Consigning them to the margins of our schools and communities does no one any good.

Importantly, the young people with learning disability through the findings in our study have demonstrated their moral worth through their insight, care and compassion for others both with and without disability. This then provides opportunities for the interplay between identity and agency as demonstrated in Chapter 7 by Andrew and Caroline and their active role as co-researchers and leaders for others labelled with learning disability but also for people without disability. In this way the narratives of our research journey are about what we all learn from Andrew, Caroline and the young people, and that rejects the ideology of exclusion Ballard (2004b). The ideology of exclusion promotes individualism, competition and indifference as a way to lead one's life. The rejection of an ideology of exclusion instead favours humanness, social justice and a capability approach in recognising reciprocity and interdependency. An ideology of inclusion promotes moral endeavour instead of moral indifference, an ethic of care instead of despair and an ethic of hope instead of hopelessness.

In this final chapter I first present a brief summary of findings from Chapters 5, 6 and 7. I then discuss the exclusionary landscape for young people with learning disability as they transition from secondary education. Second, I describe a way forward in how young people with learning disability can journey towards a good life through collective understandings, action and endeavour in the relational dimension. I offer a framework that draws together all the themes that have emerged through this collaborative journey. All these themes become elements in the relational dimension. Attending to these elements will help us all in our journey towards a good life. Our claim, as Andrew insightfully articulates, forms the title for this final chapter: “It’s all about relationships you know.” Attending to relationships at all levels and contexts will provide opportunities for these young people to transition successfully in their search for a good life. In education better relationships at a policy, school and professional level will support solutions to what Mittler (2007) views as the disjuncture between special and inclusive education policy and practice that for so long has failed these particular young people in their search for a good life. I will conclude this thesis by presenting some recommendations for “inclusive confident” policy, schools and professionals in relation to young people with learning disability.

Crucially, the narratives of this research journey reject exclusion and promote a definition of inclusion as “a way of life, a way of living together, based on a belief that each individual is valued and belongs” (Villa & Thousand, 1995, p. 11). Inclusion can only become meaningful if it means people with and without disability make a collective and reciprocal journey such as the one travelled by Andrew, Caroline and I. It is not a one way journey towards mainstream contexts, rather both people with and without disability embark and meet along the road to a better mutual understanding, appreciation and respect. This means we must reject the effects of unequal power relations and individualism that leads to restrictive and deficit thinking and low expectations.

I have highlighted the traditional connection of special education with the scientific and functional regimes of truth that has perpetuated forms of thinking and which masks the political and contested nature of the field (Allan, 2006; Ballard, 2004a, 2007; Lather, 2012; Skrtic, 1991, 1995; Slee, 1997, 2001a, 2001b, 2010). The impact of this form of thinking on special and inclusive education policy and practice in New Zealand has produced a certain kind of knowledge that, arguably, has acted to the detriment of students with learning

disability and their families. Connor and Ferri (2007) suggest “the field of special education does not recognise the politics of disability, so central to disability studies” (p. 65). As a result the socio-political contexts that have a direct influence on the opportunities that students with learning disability have as they transition from school in their search for a good life are not addressed. Education reform requires us to consider and address normative assumptions, power relations and bureaucratic irrationality that act to exclude some young people from educational and consequently life opportunity. This means all stakeholders must be fully and meaningfully involved in the process of reform from students, parents, both special and mainstream teachers, school leadership, bureaucrats, policymakers from special and regular education and other stakeholders. Only then will we have the potential to support positive and sustainable change in the lives of young people with learning disability through collective endeavour.

Returning to the research questions

In this final chapter through the discussion and conclusion I address the research questions presented in Chapter 3.

Main research question

- What does a good life mean for young people with learning disability?

Sub-questions

- What are experiences of young people with learning disability during the transition years?
- What does exclusion mean for young people with learning disability?
- What are the effects of an exclusionary landscape in school and society?
- How can the views and perspectives of young people with learning disability inform inclusive and special education policy and practice?

To answer the research questions I will draw on the key themes that have emerged from this study; an exclusionary landscape; the relational dimension and the search for a good life. The findings from our study unmasked an exclusionary landscape for students with learning disability as they make the difficult transition from school. The relational dimension is a transformative response to this exclusionary landscape and unrealised lives in education and society. The relational dimension provides solutions to how the young people can be supported in their search for a good life.

Summary of findings

In this first section, I address the first research question: *What are the experiences of young people with learning disability during the transition years?* In Chapter 5, the main theme is what the young people with learning disability want. This is summarised in Table 7 comparing their hopes and desires with their actual experiences.

What the young people want	What the young people get
Further education and training in a tertiary environment while at school and post school	Limited tertiary education opportunities and pathways
Work – work experience while at school and paid employment post school	Limited employment opportunities
Living and relationships – to be close to family, to have friends but develop meaningful relationships with other people, and to experience moving away from the family of origin and flatting with friends they choose	Limited living opportunities Limited social networking opportunities
Community – to be valued, purposeful and belong in the community by taking responsibility and contributing	Limited sense of community through negative activities and experiences

Table 7: Hopes, desires and actual experiences

Both students and young adult participants saw the value of further education and training in a tertiary environment. Some participants recognised that it was a more adult orientated

environment and could give them a better chance of employment through tertiary qualifications. Students also made the link between the value of undertaking tertiary courses while still at school and perhaps more opportunities and pathways post school. However, findings from the young adult participants demonstrated there are extremely limited opportunities to study in a tertiary environment post school and when there were these opportunities were discrete. Findings suggested discrete courses do not provide flexible pathways on to paid employment. In addition, the majority of participants were still living with the family of origin. Social networks mostly comprised family, friends and support workers. There was evidence to suggest that the young people had fewer friends once they left school and their social life revolving around family or discrete clubs. Many participants had experienced negative responses from people when out in the community.

Chapter 6 shows the exclusionary landscape in action at the macro (policy) and micro (schools' and agencies' practices and students' experiences) levels. These levels are summarised in Table 8.

Macro level	Micro level
Missing in action to policy – excluded from flagship policy work under <i>Youth Guarantee</i> . Career specific policy work excludes students with learning disability because the policy implication is that they do not require a career.	Transition practice creates restrictive pathways into vocational service day centres
Policy signals and creates a parallel process for students with learning disability controlled by the special education service industry that casts them as strangers to the mainstream secondary school process.	The transition process is mostly controlled by special education professionals Limited interaction with mainstream career services Limited transition planning in schools
Policy work fails to provide flexible pathways into further education, training that leads to paid employment.	Multiple plans act to restrict responsibility and pathways.

Table 8: Exclusionary landscape at the macro and micro level

In Chapter 7, I provided an alternative to the exclusionary landscape in Table 8 and described in detail in Chapter 6. The alternative is seen in the relationship developed through the research team that resists competitive individualism and the failure of policy rhetoric to translate in to successful outcomes post school.

Time	A relationship that evolves over time initial period of training is important as is recognising that there will be compromises by all.
A capabilities approach	Resists negative assumptions, attitudes and the professional “expert” position
Belonging	Finding a sense of belonging through the research process supports well-being
Purpose	Finding a sense of purpose through the research process supports motivation and life satisfaction
Value	Being valued for who we are. The personal and the professional relationship are valued. Gaining validity as researchers and people through presentations at conferences, seminars and to Minister
Reason	A presumption of reasoning in young people with learning disability resists exclusion in all its forms and is the gateway to our inner lives
Rights	Young people with learning disability have a right to take leadership roles in research about their lives and supports taking responsibility
Opportunities	Shifting the context can provide opportunities for liberation and freedom. Crafting identities is related to context and opportunities
Responsibilities	Shared responsibility recognises our interdependency and can overcome issues of “expert” power and control
Contributions	A strong desire to contribute to their lives and the lives of others

Table 9: Findings from the relational dimension

Together these findings showed that the clear goals and aspirations of the students with learning disability were not realised in the years after leaving school. In essence, and unsurprisingly, the students wanted to do the same sorts of things that any young person might after leaving school. They expressed views about wanting tertiary study and paid employment, having lasting friendships and intimate relationships, eventually living away from the family home as well as enjoying leisure, recreation and travel. They knew these things would take time, but equally they knew that tertiary study and meaningful work

experiences while at school were important vehicles in their desire for paid employment. They communicated that paid employment would provide the opportunity to belong in the community, be valued for their contribution and to be responsible and purposeful. With much insight, the participants were also able to rationalise their desire to be active in the marketplace with the realisation that family, friends and relationships were still the most important things in life. Above all they were overwhelmingly optimistic. Perhaps insights we can all learn from to prosper in the material world.

However, as a stark statistic not one of the 12 school leaver participants in the study was in paid employment more than five hours per week. There is no valid New Zealand data on employment or tertiary study rates for young people with learning disability partly because they are usually lost within the generic disability group. However, we do know that young people with disability in New Zealand are the least likely of marginalised groups to be tertiary educated or employed which becomes even less likely the more severe the impairment (Cleland & Smith, 2010; Statistics New Zealand, 2008). I argue the lack of post school tertiary study and paid employment opportunities for young people with learning disability is a damning indictment of how we value their contribution generally in the wider community and is reflected in an exclusionary landscape.

An exclusionary landscape

Research questions discussed:

- What does exclusion mean for young people with learning disability?
- What are the effects of an exclusionary landscape in school and society?

In this thesis, I have argued that transition related education policy and bureaucratic regimes continue to construct learning disability as a category for exclusion. These regimes heavily influence practice in schools in a neoliberal competitive education marketplace. I view the exclusion of young people with learning disability akin to what Bauman and Sennett position as the “wasting of humans” (in Slee, 2011, p. 47). Part of this complex exclusionary landscape is related to my key proposition that the special education industry unwittingly perpetuates its own specialness, which encourages the mainstream of education to abdicate its

responsibility for those students at the margins of the system (Danforth et al., 2006; Skrtic, 1991; Slee, 1997, 2001b). This is not about bad special education but more about special education practice having to respond to policy confusion about inclusion that sends mixed messages (Higgins et al., 2006). As a result practice in schools continues to consign students with learning disability down a restrictive pathway to mostly vocational service day provision. More clarity and collaboration at the policy and practice level is required. In order to challenge and reject deficit discourses and exclusion, policymakers and professionals must recognise the knowledge-power relations that are ever-present in their lives and work (Foucault, 1980; Freire, 1997, 1998).

In Chapter 1, I introduced and described DSE as the critical framework I utilised for challenging exclusion, “expert” knowledge systems, power and control. Using DSE’s critical approach I have exposed an exclusionary landscape in transition related education policy and practice (Chapter 6) for students with learning disability as they make the move from school in their search for a good life. In doing so I highlighted a number of factors including a lack of opportunity created by special education discourses, a lack of inclusive leadership, negative assumptions and poor attitudes, low expectations and a distinct lack of flexible pathways from school into tertiary education, training and employment. All these factors manifest themselves in a lack of whole-school approach when working with these students. This can be seen in the disjuncture between special and mainstream education practices and neoliberal influences on education as a marketplace founded not on collaboration but on competitive individualism. These factors reduce a young person with learning disability’s responsibility and possible contribution in school and by definition the wider community. Mostly identified as unable to compete in the education marketplace these students are then guided as a commodity along a parallel and restrictive pathway to their peers without disability, a pathway that mostly follows the well-worn path directly into a vocational service day centre. The participants in our study clearly articulated this is not what they want. Related education policy has consistently failed these particular students through, in their latest form, current programme priorities through the ongoing *Youth Guarantee* (2010c) and *Success for All – Every School, Every Child* (2010b).

Findings related to this policy work and the impact on practice in schools demonstrate that students with learning disability are – to use Bauman’s metaphors – strangers, missing in

action and collateral damage to educational reform for all students. The exclusionary landscape for young people with learning disability has cast them as people who are “in but not in” the community. I believe this is largely because students with learning disability rarely come into contact with mainstream processes and particularly career and transition education processes in schools. Instead they are reliant on special education professionals, paraprofessionals and vocational service staff who are encouraged by the system to provide a specialist service response, mostly in the student’s last year at school, which is too late and has failed to provide the pathway they so clearly want. The rhetoric of policy focusing on words like independence, choice, presence and participation has had demonstrably little impact on whether young people with learning disability can determine their search for a good life as the findings showed in Chapters 5 and 6.

In Chapter 2, I explored the literature on the theory, policy and practice of transition to begin to understand the processes at play in why some students are included and transition successfully from school while others are excluded seemingly by those same processes. Transition best practice is well articulated in the literature and has been for over twenty years. However, students with learning disability have still found it incredibly difficult to realise their goals as a new generation who “live in” the community and not having experienced institutionalisation or deinstitutionalisation.

Educational exclusion for young people with learning disability has consequences for life beyond school. The young people want, like the majority of people; to participate in the liquid modern material world as valued consumers and not as what Bauman (1998) refers to as *flawed consumers*. This is very difficult if you are excluded from the opportunities to do so by education policy and practice that creates a restrictive system and pathway that signposts a particular pathway as with placement in vocational day service provision and lifelong welfare consumption. Most young people with learning disability knew that to actively participate in the material world would require further education and training that might lead to paid employment. However, paid employment does not necessarily provide access to a sense of belonging or indeed a good life (Hall, 2010) and has often meant being isolated and poorly paid for people with disability (Bennie, 2005; Bray, 2003). I argue though it does provide for purpose and to feel valued in one’s life and this is an important element in anyone’s search for a good life. It also allows more opportunities to “live in and with others” and then one can

be recognised for whom one is and valued for what they contribute. Being recognised through the status of being employed allows the young people with learning disability to contribute to school and the wider community not only in economic but in relational terms as a student, fellow citizen and human being.

As described in the second half of Chapter 2, the contemporary responses to people with learning disability by education and social welfare services over the last twenty-five years has, I argue, failed to make any real difference in their search for a good life. They remain largely under the control of these systems and services that mostly manage their lives through bureaucratic processes and corporate/managerialist discourses (Rapley & Ridgeway, 1998). These service industries and their workers are well meaning but continue to case-manage, assess, train, refer, advocate, audit and provide services (Westcott, 2003). The findings from the young adult focus groups clearly demonstrated that students with learning disability were unlikely to realise their goals and aspirations in the years after school. These years are seemingly defined by limited opportunities in segregated day provision, socialising in discrete clubs or with family or support workers and very little further education, training or employment (Westcott, 2003). When there was further education and/or training, importantly it did not appear to provide a pathway or move them forward in their search for a good life. Most often it meant either returning to or starting in a vocational service day centre and continuing to live with the family of origin. The young adults' narratives described an unwelcoming community with few opportunities for activities they saw as purposeful or valued. Mary's incident with the bus driver and John's experiences of verbal abuse described in Chapter 5 portrays a lack of empathy or caring by people in school and the community at large.

In Chapter 3 I explored theoretical frameworks as tools for thinking about the social construction of learning disability. This theorising encouraged me to understand knowledge as co-constructed, negotiated and provisional. This relational view of mean-making challenged dominant assumptions about young people with learning disability and championed ethical, moral and democratic alternatives. Critical Freirian and Foucauldian interpretations and analyses of knowledge, power and democratic resistance provide an understanding of how to locate the lived experiences of young people with learning disability. These interpretations and analyses allowed me to exercise a critical curiosity about whose

knowledge counts and are privileged. I used Bauman to understand and position young people with learning disability within liquid modern society through his sociological critique of social inequality and marginalisation. These critical ideological, epistemological and ontological understandings paved the way for the methodological decisions I made and described in Chapter 4.

In Chapter 4 I provided a detailed justification and description of the PAR approach adopted for the study and the methods used for data collection and ongoing analysis in what was an iterative process. The use of extensive related PAR methodology literature was drawn on to justify and describe our particular focus group instrument. I felt the extensive literature drawn on and my description was required in my attempts at deeper understanding. A discussion of ethical issues and my position as researcher in the study concluded this chapter.

Using DSE's critical lens in the findings reported in Chapters 5 and 6 provided me with an understanding of how special and inclusive education policy and practice has masked the underlying control and power exerted over the life outcomes of students with learning disability. The views of the young people with learning disability through the findings chapters and importantly the research team, clearly communicated a desire to take responsibility and be active contributors to their lives and the lives of others in the community, if provided the opportunity. However, the findings show the participants mostly made the transition from a segregated education setting to a segregated vocational service setting. The findings in our study support the history of young people with learning disability as largely identifying community as inextricably linked to service systems whether during their compulsory education or after it (Metzel, 2004). I view this "false" transition as little different to the continuing social, political and cultural separation of people with learning disability and which still reflects a form of institutionalisation in all but name. By this I mean that young people with learning disability mostly attend local vocational service day centres with up to 150 clients on their books. This results in large groups of people corralled in day centres with seemingly little purpose and value in their lives. To date new forms of provision and redesign of vocational services as articulated in the Office for Disability Issues *Enabling Good Lives* report (2011) and its current demonstration in Christchurch has yet to make any impact on the young people in this study and their search for a good life.

In Chapter 7 as a positive response to the exclusionary landscape I have told the story of the research team's journey and the reciprocal, trusting and caring relationship that emerged through the participatory action research approach adopted. The research team's journey acknowledges and celebrates our interdependency (Ballard, 2007; Freire, 1996; Heshusius, 2004). I take up this counter-narrative to exclusion later in this chapter through a framework of elements in the relational dimension.

The young people with learning disability in our study want to find a sense of belonging in society. I suggest being in further education, training and/or paid employment provide opportunities for gaining a sense of purpose, value and belonging in Western societies. The young people with learning disability in our study knew perfectly well that consumption in the material world was a means to an end. They clearly understood and considered the most important things in life were concerned with their relationship with family and friends because of the mutual love, care, trust and reciprocity that existed. This clarity in their narratives can be utilised to teach those without disability a thing or two about a good life and the balance between freedom and constraint and the "false truth" of choice and commoditisation in liquid modern life (Bauman, 2008, 2011).

Education and social policy driven by neoliberal discourses of independence, self-determination and choice in the market will continue to exclude young people with learning disability and excuse education and society from its obligation. Another way is needed. Rather than exclude through promoting independence, a more fruitful, humanistic and democratic path is to provide opportunities for the recognition of our relative interdependency. Interdependency acknowledges and promotes everyone's contribution and allows for taking responsibility and gaining a sense of self as active in the society rather than only passive recipients of care and support. Being seen as active through choice and control in the material world for people with disability in New Zealand is currently being enacted through the recent personalisation of services and new models of support developed by the Ministry of Health. This policy direction influenced by market ideology then positions young people with learning disability as consumers of welfare support rather than active consumers. As McClimens and Hyde (2012, p. 141) warn we need to "understand the consequences of constructing the person with learning disability as a consumer in a marketplace of goods and services where that individual has limited rights and resources." My argument being these

particular young people with learning disability have the capacity and capability to belong as active consumers if provided flexible pathways into further education, training and employment. Once identified by the wider community as actively contributing and taking responsibility through further education, training and employment there will be opportunities for mutual trust, respect, reciprocity and greater understanding.

These young people are clearly capable of paid employment but need those in power to acknowledge this and then ensure they are included and benefit from the same career and transition education processes for the majority. Employment must come through creating workplaces and communities where all are valued for their contribution. Only when young people with learning disability move beyond presence and participation to a sense of belonging in society will the privileged members of that society acknowledge and celebrate difference and diversity through mutual understanding and acknowledgement of our interdependency. No doubt support will be required but it needs to be well trained support that creates natural supports rather than specialist support controlled and managed by the special education and social welfare industries.

To further my discussion of the exclusionary landscape for young people with learning disability I utilise the following descriptive phrases that build on Bauman's use of metaphor: "missing in action and collateral damage"; "policy restricts pathways"; and "tales from the market and the liquid-modern world." Utilising these phrases I provide further discussion of the systemic and structural issues that young people with learning disability face during the transition process from school.

Missing in action and collateral damage

Young people without disability leaving school today are expected to deal with a career path that is no longer stable, linear or singular and have to deal with complexity and a distinctly non-linear pathway (Nairn et al., 2012). In comparison young people with learning disability are still expected to plod along in a predictable linear pathway directly into a vocational service day centre where it can be said they mostly spend their days in supported loitering. This restrictive pathway acts to deny them the opportunity to belong, be valued and be purposeful in society as a mutual benefit for all citizens. The young people in our study

wanted to actively take part in the market but as previously stated they did not see it as all-consuming in their lives.

Slee (2011) and Bauman (2011) both view collective moral indifference and social inequality as being causes of exclusion. Many exclusionary practices are often masked and hidden within deeply embedded cultural practices (Corbett and Vines, 1999). The findings in this thesis have uncovered exclusionary policies and practices as described in Chapters 5 and 6. I used Bauman's metaphors to describe students with learning disability as other and operating in a parallel place that is not valued by mainstream education and therefore less worthy. The students are *missing in action* at the macro level because recent related education policy has failed to adequately include and provide flexible pathways for these students post school. They are *missing in action* at the micro level in schools because they do not generally come into contact with the mainstream career and transition education framework. They are *collateral damage* to mainstream education because they are not required to have a career like students without disability. The assumption is they will mostly transition into a vocational service day centre and not into further education, training and employment.

I have argued in this thesis the influence of neoliberal policies has promoted a climate in schools, which acts against students with learning disability and presents them as a culturally distinct group and excluded as a result. They are largely consigned to operating in a parallel transition process as a mutually beneficial relationship between special education and mainstream education (Slee, 2011). Roger Slee speaking at the International Special Education Conference (ISEC) conference in Manchester in 2000 described schools becoming the "cartographic police" and exclusion proceeding through "deep structural and broad cultural mechanisms to invigilate a shifting spectrum of diversity." Slee (2011, p. 48) describes exclusion as "characterised by ubiquity and antiquity." In this sense it is part of our past and is everywhere reflecting the very fabric of our lives and identified by its resilience. This requires transformative action to expose, challenge and reject.

Policy restricts pathways

I have highlighted the failure of policy to influence the continuing exclusion of students with learning disability. I have suggested policy has created the conditions by which these

particular students are excluded. The Child Poverty Action Group in New Zealand (2011, p. 182) states “education policy has a part to play in unequal educational outcomes in the way it influences, directs and resources schools, and allows and encourages teachers and principals to exercise their agency.” I have argued that despite a good deal of inclusive rhetoric in government transition related policy work there is still a significant and worrying gap between special and inclusive education policy and how it impacts practice and outcomes for students with learning disability. Mittler (2007) reinforces this view from the UK:

We now have some hard data on how families and young people themselves experience the process of transition which illustrate the yawning gap between policy and practice which has been experienced by young people with learning disabilities over many decades (p. 17).

Mittler’s description has much relevance to the current special and inclusive education policy confusion in New Zealand. The existence of inclusive policies and legislation does not guarantee wide ranging changes in attitudes and practices within education (Higgins et al., 2006; Kearney & Kane, 2006; McMenamin, 2014). The right to inclusion in government policy across Western countries has been challenged by many including what Barton (1992, p. 2) calls “romantic visions and idealistic rhetoric” and what Slee (1999, p. 125) calls “fashionably inclusive discourse.” Inclusion must be more than simply rhetoric in order to truly transform education in such a way that it recognises all students as valid contributors to their lives and the lives of others. As such it is not something that can be bureaucratically measured and then massaged to produce a benchmark for “80% of schools being fully inclusive and 20% well on the way by 2014” as with the Ministry of Education’s interpretation for “inclusive confident” schools (2010b). As a process inclusion is contingent, fluid and defined by its ebb and flow in schools as they respond to a multitude of factors over time such as changes in leadership, resourcing, student numbers or the next policy or curriculum initiative. What must remain stable throughout are values, equity and opportunity and the recognition of our interdependency as human beings. It is not a finite path but a journey where special education paradigms must be replaced with inclusive democratic paradigms (Ballard, 2007; Kearney & Kane, 2006; Slee, 2011). Part of the problem is that there is no clear definition by the Ministry of Education about what inclusive education

actually means and therefore this has implications for how education is structured, resourced, and practiced (Higgins, et al., 2006; Kearney & Kane, 2009).

My exploration in Chapter 6 of relevant education policy highlighted this confused and contradictory landscape that I argue has excluded and worked against the flexible transition pathways for students with learning disability from school. The Ministry of Education continues to frame the term inclusion within special education discourses (Higgins, et al., 2008). As a current example the Ministry talks about inclusive practices shown in their latest reincarnation in contracting the NZCER to develop an Inclusive Practices Tool (IPT). The IPT will build on the set of indicator questions developed by ERO in 2010 as part of the response to *Success For All, Every School, Every Child*. These questions are being used by ERO to review how well schools include students with high (special education) needs. ERO's task is to audit and report on schools' performance towards this goal. This then becomes about defining inclusion to 3% of the school population and how well schools mainstream them. It carefully avoids the contradiction of an inclusive education system with special schools and the increasing resilience of special education in New Zealand (McMenamin, 2011; Gordon & Morton., 2008). This contradiction can be seen to reinforce a special education model focusing on resource allocation and improving professional practice in order to attend to a distinct population of students who in the rhetoric of policy are required to be "present" and "participate" in a fluid, individualised, competitive education marketplace without any notion of how they might gain a real sense of belonging. This contradictory rhetoric begs the question how the majority of students in our study can be present or participate when they attend a special school?

Equally complicit is the policy emphasis on "independence" which makes no sense when in reality no-one is fully independent. We are all dependent to a greater or lesser extent and this varies and changes over time. As an alternative I have suggested the notion of interdependence as a more useful concept that recognises the relational, reciprocal, moral, trusting, evolving nature of the term being better suited as a descriptor for how we live our lives in relation with others.

Tales from the market and the liquid-modern world

The “let the market decide” proposition in many contemporary Western societies has alienated the *stranger* as other in these fluid times. Cast as *strangers* has made it challenging for young people with learning disability in their search for a good life. Bauman views culture in liquid modern times as a move away from structure to the acceptance of all “tastes with impartiality” and “a temporariness and inconsequence of choice” (2011, p. 14). This allows for networks to replace structures so that making connections, breaking them and re-engaging replaces the requirement for determination, trust and a sense of belonging. In this environment relationships are reduced to temporary, peripheral and constantly re-negotiated forms.

Bauman (2011) makes the connection between the freeing of market economies from the non-economic restrictions of social and political action and the “gradual transformation of the concept of culture” (p. 14) from the project of enlightenment to seduction. He views seduction as temporary and ongoing. Therefore the function of culture moves from satisfying existing needs to constantly creating new ones. Schools can be implicated in this seduction, being compelled by the system to flaunt themselves for their education consumers, namely students now known as learners (and their parents) who require flexible, marketable skills, in order to succeed in the transient, consumerist pursuit of the material world.

The link between education, the economy and the labour force is embedded in and fed by the market economic mantras of neoliberal policy. Why then do students with learning disability who say they want to belong in this market melee, find it such an exclusive club and therefore so difficult to gain access to? I suggest the neoliberal forces of marketisation in New Zealand education (Ballard, 1999; Higgins et al., 2008; Gordon & Morton, 2008) has created an environment which has encouraged schools to abdicate their responsibility for students like those with learning disability, who will not perform in the same way as the “norm” (Slee, 2000). In education and society today we tend to evaluate young people by their worth as a commodity or by their market value (Bauman, 2011 p. 124). In this sense young people with learning disability are considered as having limited market value and are therefore identified as failed consumers or as Bauman contends *flawed consumers* in education and consequently society.

In New Zealand the marketised education system reinforces competition among schools where consumer choice is promoted as a key benefit. There is competition among secondary schools for credentialised students and in many ways among special schools that also compete with each other for those students who have their own credit rating as with ORS funded students. An ORS credit rating can be seen in a negative way as it acts to commoditise the student in terms of their monetary value as a way to judge how they are included. Losing an ORS funded student to another school has almost immediate financial implications for a special school and which can affect staffing.

It follows that those education consumers who have the greater material and cultural resources are those generally better able to control and gain from their choices. Market ideology positions the right of the individual to that choice as a key driver for more “efficient” and “effective” schools. However, this education landscape produces students who succeed and significantly those who fail (Allan, 2005; Ballard, 2007; Slee, 2011). In New Zealand currently there is a persistent and significant “tail who fails.” Those who “fail” are mostly those to be found at the margins of the education system such as students with learning disability. Students with learning disability experience a restrictive landscape that fails to position them as having the currency or credibility to participate let alone belong in this education consumptive marketplace. Often already identified and established in special or secondary school units as lifelong social welfare consumers, it is hardly surprising these young people then make the transition from school and continue to receive “benefits” from the welfare state in segregated community settings as devalued, incapable, uncreditworthy individuals. Thus an individualised, market model of choice in education can be seen to disadvantage students with learning disability who are not free to determine that choice (Smith & Routel, 2010).

As a de-valued and marginalised group who lack the opportunity and therefore the experience to fully participate and thus take responsibility, let alone belong in this liquid modern cultural project, young people with learning disability are deeply disadvantaged in their search for a good life. Identifying and naming exclusion in education and society is crucial for creating possibilities for inclusion and thus educational and societal transformation. Only when we have a critical understanding of deficit discourses and the invidious influence of market ideology in education will we transform knowledge-power relations in meaningful ways

(Freire, 1997, 1998; Graham & Slee, 2008). This is not only about placement in a special or secondary school as a dual model of education. This is more about how we can challenge assumptions concerning market value, consumption, normality, independence and competence by Western culture as the only way to understand what a good life might mean.

Utilising Bauman's social thought and looking through the DSE lens has allowed me to critically explore, expose and challenge how knowledge and power acts to create inclusionary and exclusionary outcomes (Graham & Slee, 2008; J. Connor, et al., 2008; Gabel, 2005; Smith, Gallagher, Owen & Skrtic, 2009)). The clear voice of the young people with learning disability presented in the findings chapters express a desire to be included not excluded from educational opportunity. In using DSE's critical lens I have challenged traditional special education understandings of learning disability and difference that focuses on aspects of identity and experience that are individualistic. I have suggested this acts creates low expectations, deficit expert views and acts against effective collaboration and relationship building between special and mainstream education.

An alternative to exclusion

In seeking solutions to the continuing exclusion of young people with learning disability we must acknowledge our interdependency as human beings and citizens in the community through taking shared responsibility. If we acknowledge our interdependency young people with learning disability are then viewed as capable and valued, purposeful and contributing and this will begin to create opportunities for them to find a sense of belonging and take on more responsibility in their lives. Bauman (2000, 2011) sees the unpredictable liquid modern phase in contemporary western society as the abandonment of a model of social justice as the ultimate goal for society. In hope and through the overwhelming optimism of the young people with learning disability I see the wealth of expertise in both regular and special education that if nurtured in inclusive learning communities and school consortia has the capacity to effectively collaborate and share expertise and greater understanding for the benefit of all students.

I consider solutions to the continuing exclusion of young people with learning disability from the journey towards a good life are to be found in the relational dimension. In seeking

solutions Bauman's theory of agency is founded on the pre-societal form of morality. This extends the being *for* the other to being *with* the other as reciprocal and interdependent and allows for democratic forms of moral concern (Dawson, 2012). Thus we need to care and hope and take risks within the relational dimension.

In the next sections I draw on the relational dimension as a framework that has emerged from the research journey themes as further discussion in the search for a good life. I offer a framework that attempts to illustrate the complex nature and web of elements that influence anyone's journey towards a good life. The utility of the framework is relevant for all young people and not just those with learning disability. I use it to further my discussion in beginning to look at possible solutions for how young people with learning disability can journey towards a good life.

A framework for our search for a good life

Research question discussed:

- What does a good life mean for young people with learning disability?

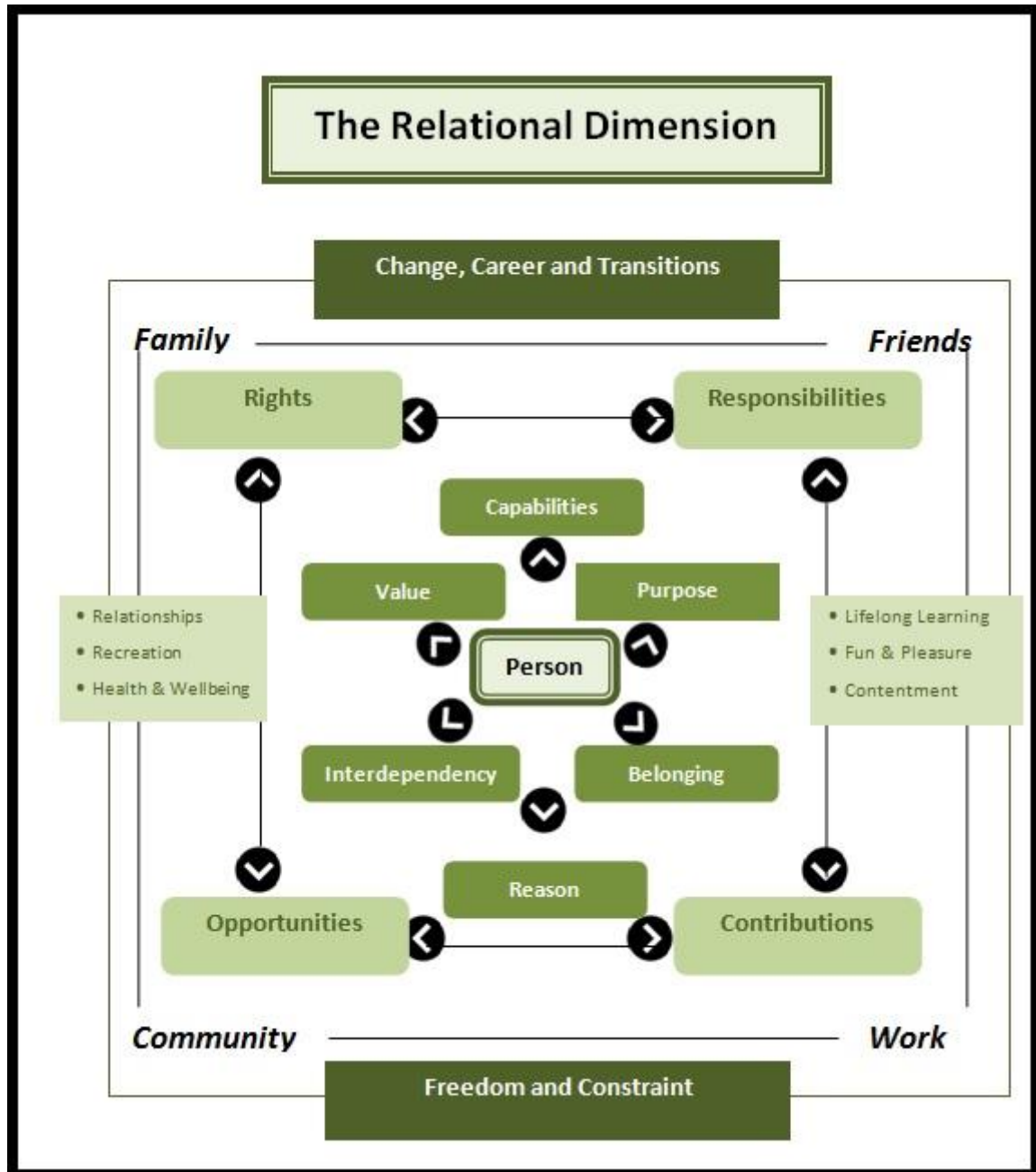


Figure 15: Elements within the relational dimension in the search for a good life

I use the framework in Figure 15 to continue my discussion and consider the myriad factors that impact the journey towards a good life.

Work – paid employment

As described in Chapter 5, the young people with learning disability in our study overwhelmingly wanted paid employment and so this must figure prominently in their search for a good life. A New Zealand study found that people with learning disability are motivated to work for the same reasons as the rest of the adult population, “real pay for real jobs” (Reid and Bray 1998). Arguably there has been no tangible improvement in paid employment opportunities for these young people since the inception of models like supported employment over twenty years ago in New Zealand that was hailed then as the great solution for people with disability and paid employment (Bennie, 1996; Bray, 2003). As I highlighted in Chapter 1 from LSTS data, not one out of 68 students leaving school over a three year period between 2008 and 2010 went into what might be considered full-time paid employment. In addition not one of the young adults in our study was in paid employment over 5 hours per week.

Ideologically, the rise of capitalism saw the separation of work from home which gave rise to the construction of individualism. This then became a way of understanding disability where the rise of capitalism constructed disability as an individual pathology. This was as a result of a distinction needing to be drawn between those considered “able bodied” and by implication able to work and those who were considered “dis-abled” and not able to work. The young people in our study held a clear desire to be productive and purposeful rather than begrudging acceptance that learning disability constitutes a burden to others. Work in all its many and various understandings and forms can be considered a key vehicle for obtaining a good life in capitalist societies. The participants strongly rejected the dependent burden narrative and instead showed their capabilities, as demonstrated by Andrew and Caroline through the research process, which could provide them with tools to resist social, political and economic marginalisation. A reciprocal relationship can exist where employment is situated at the centre of both an individual and collective effort to reconceptualise traditional notions of learning disability as a social or public burden. Embedded within the goal of seeking some form of material self-sufficiency, the young people with learning disability communicated a

rejection of more traditional notions of dependency on others, which they acknowledged as an undesirable alternative to paid work.

A number of the young people were able to articulate an understanding of the value of paid employment providing the money to obtain the material things in life. They had a keen sense of employment providing the financial and social means to do the things they see young adults without disability doing such as socialising, holidays and flatting. In preparation for employment many students with learning disability had undertaken work experiences while at school. This supports similar findings by Levinson & Palmer (2005) and Rogan, Grossi, and Gajewski (2002), where employment was considered by the research participants a central component of their lives, providing not only economic benefits, but also a social network and a way of being valued in the community. Research by Forrester-Jones et al (2004) also found that employment was seen as a pathway to social networks by people with learning disability. Employment was considered by the young people in our study to provide opportunities for not only greater financial freedom but enhanced self-esteem as found in research by Fabian (1992) and Lehman et al. (2002).

Many of the young people with learning disability sought employment to provide them with a sense of contribution or giving back to society. Some young people with learning disability conceptualised their employment in terms of helping others, even if this was not directly related to their role. There was a feeling that deep-seated values of reciprocity can and should be expressed through work. Many young people with learning disability felt that work was more satisfying if personal values and work roles were properly aligned. This is something not usually found in literature for people with learning disability.

However, I concur with the work of Douse (2009), Johnson, Walmsley with Wolfe (2010) and Redley (2009) in the UK and Australian contexts who argue that we must be acutely aware that placing paid employment as the magical key to providing a good life is only part of the story. This is because work has often been high-jacked by neoliberal policy to further new “technologies of welfare” (Douse, 2009, p. 573). Neoliberal policy has created a specialist service response that utilises outcome measures exemplified by supported employment agencies placement data. Too often this data is misleading and acts against the

more important work of creating natural supports in the workplace and community (Douse, 2009).

Employment should be an important component in the process of individual and collective identity formation. Employment for anyone provides a purpose in life, a reason to get out of bed in the morning, a structure to frame the day, a place to develop relationships. Young people with learning disability are being denied this opportunity. The crucial aspect of employment opportunities for young people with learning disability is that it can be interpreted in many different and flexible ways that acknowledge the capabilities of people with learning disability rather than judging them on deficit assumptions and what they are incapable of. There are many examples around the world where sustainable paid employment opportunities have been successfully created based on the recognition of mutual support and capabilities in how young people with learning disability can enhance the environment they enter. A good example of this is Project Search training to employment internship programme that has been successful in providing sustained, paid employment for young people with disability in the US, UK and recently in Australia (Nabi, Holden & Walmsley, 2010). It is particularly suited to the young people in this study and offers an internship model for students in their last year of school with large employers like hospitals, banks, universities and manufacturing companies. The interns usually go through four onsite work rotations with the firm over the year. Importantly, there is a high success ratio of interns entering full-time paid employment after the year is completed often with the employer they did the internship. Having visited many Project Search sites in the US and UK over the last couple of years I have seen firsthand its value and potential as a solutions focused model for NZ. Crucially, it is a programme that builds natural supports in the workplace. Work colleagues without disability develop an appreciation of the capabilities of young people with learning disability and acknowledge the growing value of their relative interdependency. This resists deficit discourses and encourages people to be seen for who they are and what they offer over time.

The young people mostly felt that paid work afforded them a sense of status and worth. Many conceptualised work to be about personal success in overcoming low expectations of their capabilities. Work was seen as confirming to themselves and others that their identity was not only as learning disabled. Work was related to emotional health and well-being where they are seen as capable by others. However, the emerging influence of policy related to the

personalisation of services that support people with learning disability run the risk of placing responsibility on the individual to create work opportunities rather than rethinking work so it embraces all (Johnson & Walmsley with Wolfe, 2010, p. 103).

In addition to programmes like Project Search there are other innovative ways of conceptualising work that provides purpose, value and a sense of belonging for the young people in this study. New models of work based on social, mini and micro enterprises with the focus again on capabilities and strengths of the individual at the core with employment opportunities built around them as in the story of Cameron and the innovative company CAM CAN (<http://cam-can.com.au>). Cameron is a young man labelled with profound learning disability and is now a small business owner and operator; he lives in his own home and has natural supports around him. He is valued for his contribution through the innovative use of a network of family, friends, community members, neighbours and support services. Being a business owner employing his own staff sends messages to the wider community about his identity and status within it. The business enterprise is also founded on the relational aspects of interdependency where both employer and employee benefit from each other practically, socially and emotionally.

Family

The importance of family and in particular parents was a key finding in our study and supports the literature (see for instance Hornby, 2010). The large majority of young people were living at home with the family of origin. The literature tells us the role of family is important for the successful transition of marginalised students (Hornby, 2010; Morningstar, Turnbull, & Turnbull, 1995). The involvement of parents and siblings is equally important during transition planning (Chambers, et al., 2004). Students with learning disability appear more engaged in the transition planning process when families encourage involvement (Morningstar et al., 1995).

Research on family interactions during the transition from school for young people with learning disability highlight the tensions that are often present (Mirfin-Veitch, 2003). Parents will often reinforce their son or daughter's childhood dependency through a fear of uncertainty that the future often holds rather than promoting greater self-direction and

autonomy (Mill, Mayes and McConnell, 2010). Zetlin and Turner (1985) found that some young people with learning disability resented what they perceived as overzealous control by their parents. Ward, Mallett, Heslop and Simons (2003b) in their study on the transition to adulthood for young people with learning disability found they appreciated the sense of security that family provided. The findings in our study support the strong bond and reciprocal nature of the relationship between the family and young person with learning disability. There was an understanding by the young people with learning disability that family ties were very important and they felt their role within it was valued. This close reciprocal bond moves away from notions of dependence or independence to a space where interdependency can be recognised. This interdependency is enhanced by the fact that parents and families are closely involved in the lives of young people with learning disability and for longer than for those young people without disability.

The narratives of the young people expressed a love and respect for their family and in particular the mother but at the same time a desire to move away at some time and “live with” the wider community. These desires are the same as any young person wanting to take on more responsibility for their lives. Importantly, this is not about seeking independence and getting away from family but about a desire to take responsibility and contribute to life and the wider community in general. These young people wanted an identity in the community outside of their family and friends or paid or volunteer support workers. This is significant because there is a desire to seek a life in relation to people without disability.

Friendships

The young people in our study greatly valued their friendships. When compared with people without learning disability, the social networks of people with learning disability have been found to be smaller, with proportionately fewer friends and contain a large proportion of support workers (Rosen & Burchard 1990; Forrester-Jones et al. 2006). We did not measure social networks quantitatively in our study but the narratives of the young people suggest their situation mirrors other research.

Although friendships are important throughout the entire lifespan, they are especially so in a young person (Crosnoe, 2000). A variety of studies have examined the link between

friendships and a variety of outcomes in young people generally (see for instance Berndt, 2004). According to Hartup and Stevens (1997), young people spend almost a third of their waking time in the company of friends. During teenage years, young people become less dependent on their parents and turn to their friends for emotional support (Berndt, 2004). This was not the case for the young people with learning disability in our study who still mostly relied on their parents and family members many years after leaving school for both emotional and more practical support. There is research evidence to suggest that once students with learning disability leave school their social networks are reduced even more, particularly other friends with learning disability who they lose touch with (Small, Raghavan & Pawson, 2013).

Raghavan & Pawson (2008) conducted a small-scale study of the transition to post school for young adults with learning disability. Findings indicated that very soon after (2 years) leaving school the young adults suffered greatly reduced social networks mostly as a result of limited post school opportunities. This supports the findings in our study where placement in a vocational service day centre usually indicated a reduction in the number of their friends in comparison to when at school. Arguably this is true of any young person leaving school but as research has shown social networks are related to the opportunities available to one through everyday activities undertaken in the community with others. The trick is to be undertaking those activities with people with and without disability who have shared interests.

Research has shown that friendships for people with learning disability with people without disability tend to be superficial or more like an acquaintance (Clegg & Standen, 1991). This was certainly the case for the young people in our study. There is often an assumption that people with learning disability cannot have reciprocal friendships because they do not have anything to “offer” the friendship (Mirfin-Veitch, 2003). The narratives of the research team demonstrate this is not so. However, the findings from our study corroborate research by Emerson and McVilly (2004) who found that the majority of friendship activities took place with other people with learning disability.

I suggest from our findings that the more extensive your social networks the more opportunities you have to develop friendships and the more restrictive your social networks

the fewer opportunities you will have. It is important to acknowledge that people move in and out of different communities and that this changes over time and circumstances which will impact a person's social networks. There is the wider community at large but there are also smaller communities that we all belong too and develop different relationships within. The young people with learning disability derived a good deal of support from the discrete clubs they belonged to and that would be the same for most of us whether as a member of a walking group, video gaming club, rugby club, yoga class or the Upp Club like Andrew and Caroline. Identifying with similar people who have similar interests is natural and changes over time as we enter different phases in our lives. It is important though that we are not restricted in our opportunities to interact with people with and without disability so we can develop our social networks as required. For example Andrew has begun to interact with a number of different communities or groups in the last few years. He has his family and friends from school that he still keeps in contact with. He has the networks of people from school, day centre, the Upp Club, the university, theatre group, and voluntary workplace, his flatting, my family and so on. Together they make up the social networks that Andrew interacts within. I suggest that going into tertiary study, employment and being involved in purposeful activities and organisations enriches your social networks which in turn have the potential for forming friendships.

Caroline's social networks have grown and extended in the last couple of years as she has become known as an "expert" and advocate for people with learning disability. She is now on a number of committees related to disability that has brought her into contact with a very diverse range of people both with and without disability. Crucially, she has understood that her growing status and identity provides more control over her life and the lives of others that she represents. Her confidence has grown immeasurably as her skill and willingness to engage with people less familiar. These are important understandings about life for anyone.

Research has shown that friendships between people with and without learning disability are relatively unusual but do exist (Gladstone, 2005; Lutfiyya 1991; Taylor & Bogdan 1989). In these cases they often emerge out of an earlier professional or caring relationship. In the case of Andrew, Caroline and I this was true in respect of our initial teacher/student relationship. However, the importance of a social relationship can be viewed in terms of its reciprocal, caring and emotional engagement. Our relationship has moved beyond the professional to the

personal and the professional as described in Chapter 7. The personal in our friendship is defined by its reciprocity, care and mutual trust.

Community

Community is not where a person is living, but where the person feels they belong, shares experiences and has valued relationships with others. The amount of participation in a community (living, education, employment, recreation, etc) is directly related to the skills and resources of the person and importantly the skills and resources of the community where the person wishes to find a sense of belonging.

In this thesis I have argued that young people with learning disability largely operate in a parallel community where they can be described as “in but not in” community. Findings indicate they have very little interaction with people in the community who aren’t either family, other people with learning disability or special education and social welfare workers. Our findings are supported by the literature (Johnson, Walmsley with Wolfe, 2010; Metzel, 2004; Westcott, 2003). Activity in the community tends to be in discrete clubs, groups or activities. Contemporary approaches to the perceived problem of learning disability described in Chapter 2 continue to exclude and marginalise young people with learning disability from finding a sense of community belonging. It is fair to suggest there has been progress made in improving the social and material conditions of people with learning disability. However, even though young people with learning disability are “in” the community it does not mean they are finding a sense of belonging through meaningful interactions and activities with people with and without disability. Young people with learning disability are present and participate in the community but our study findings suggest there are still barriers in the form of negative assumptions and attitudes as well as structural barriers promulgated by neoliberal influenced education policy and practice. I argue that flexible pathways into tertiary education and employment would provide young people with learning disability a greater opportunity to be valued, have purpose and take responsibility for their lives in collaboration with people with and without disability. This will happen only when the wider community is involved in the process rather than a specialist service response.

I now move on to a discussion of other elements that have emerged through the findings. They are: values, interdependency, belonging, purpose, reason and capabilities in our search for a good life. Firstly, we all want to be valued for who we are and what we contribute. I then suggest we are all interdependent to some degree and this recognition will overcome individualised understandings. Thirdly, a fundamental human desire is to feel they belong and this provides a feeling of well-being and acts to resist exclusion and marginalisation in society. Fourthly, I suggest we all need purpose to enrich our lives. I briefly consider how the ability for reasoning has often been used to exclude young people with learning disability in their search for a good life. Lastly, I look at what a capabilities approach has to offer young people with learning disability.

Values

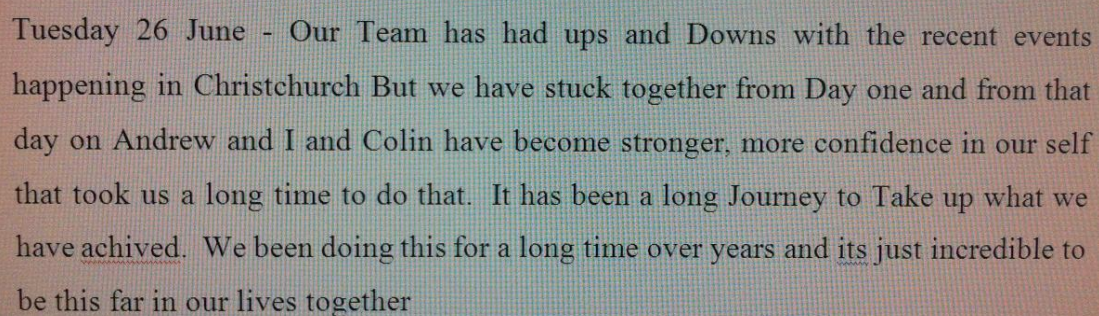
It appears from the findings in our study that values strongly influence inclusionary and exclusionary policy and practice (Ballard, 2004). At the macro or policy level they reflect government priorities and at the micro or school level they reflect what school leaders, professionals and staff believe and how their values influence practice. Ainscow, Booth and Dyson (2006) identified a number of values they viewed as important including compassion, equity, respect for diversity, entitlement and a sense of community. Kearney (2009) in her New Zealand research study found a close link between the values identified by Ainscow et al. and issues with a lack of equity, entitlement and fairness generally for students with disability. In our study as with Kearney's the relationship between values and practice was evident and exclusionary. For example at the micro level in schools students with learning disability did not generally have access to career specialists in schools or their resources whether in a special or secondary school setting. Our findings suggest this situation simply encouraged already established relationships between special education staff and those from local vocational day services to the detriment of those with career specialists. In addition, the fact that the vocational service had a transition contract from the MSD to work with ORS funded students in their last year meant that special education staff often deferred responsibility for the students to the vocational service transition coordinator. Unsurprisingly, this resulted in most students transitioning directly into one of the many local vocational services and alarmingly in some cases directly into the vocational service that the coordinator

was employed by. This situation acts against students with learning disability requiring a career because they transitioned directly into a vocational day service.

In addition the responsibility for transition planning was with the special education teachers rather than a career specialist which resulted in ingrained pathways that led too often down the pathway to the vocational service day centre.

Interdependency

Interdependency is an important term to emerge from our study and acts both as a rejection of individualism and allowing us to move away from the term dependency while challenging the notion that anyone is fully independent



Tuesday 26 June - Our Team has had ups and Downs with the recent events happening in Christchurch But we have stuck together from Day one and from that day on Andrew and I and Colin have become stronger, more confidence in our self that took us a long time to do that. It has been a long Journey to Take up what we have achived. We been doing this for a long time over years and its just incredible to be this far in our lives together

Figure 16: Reflective account from Caroline's research diary

Caroline's diary excerpt above (Figure 16) aptly describes our interdependency and the research as a journey and how we have grown individually and collectively through the relational process. It offers insight for how people with and without disability can find reciprocity and mutual trust in their relationship. The hint at our lives on a personal and a professional level over an extending period is important to understand how the self and other can find mutual support through interdependency. By rejecting the "ethos of individualism" (Charlton, 2006, p. 218) that often defines notions of autonomy and self-determination we acknowledge the importance of our interdependency. Caroline's diary excerpt acknowledges our interdependency and uses it to celebrate collective achievements in the relational dimension. Caroline's narrative is full of first person plural as with "we," "us" and the "our."

I suggest there is much to be gained from the construct of interdependency in how young people with learning disability can shape and determine their lives. Student self-determination may infer notions of empowerment, agency, and human rights but current interpretations by the Ministry of Education reflect discourses focused on normalcy, independence and special needs rather than a discourse of diversity, interdependence, democracy and social justice. The findings in our study demonstrate that young people with learning disability can act to shape and determine their lives if provided the right support and opportunity. They do so through the recognition of our relative interdependency. Rejecting individualism creates spaces for mutual and interdependent expressions of self-determination. Indeed the methodology utilised in our study has attempted to privilege the diverse and ever-changing perspectives of self-determination that young people with learning disability hold and as such adds much needed theorising to the construct. The young people in our study demonstrated agency despite the exclusionary landscape they experienced during the transition process. Professionals must look for inclusive, challenging and naturally occurring opportunities for fostering skills associated with self-determination and not teach in isolation. Being able to advocate for oneself is important for young people with learning disability and is best realised through inclusive, co-operative situations rather than in isolation with only other young people with learning disability. This was demonstrated through the research team process. Andrew, Caroline and I in collaboration with others at conferences, seminars and meetings through the research process recognised our interdependency as mutually constructed. Throughout the research process and continuing to this day we engaged in a dialogic process that is defined by the social relationship and its emotive and political obligations. Caroline has utilised this political element in her advocacy work as chairperson of a regional People First committee. Andrew and Caroline have expressed a desire for recognition and rights. Through an ethical dialogue and exchange the three of us have realised the opportunity to be responsive to others in order to reassess and reinterpret our own lives.

Peter Isaacs (1996, p. 43) describes interdependency in relation to the search for a good life.

The “good life” is one of freedom within the community: interdependence in which one strives for individual needs alongside communitarian needs, where the community values, celebrates and responds energetically to diversity.

Isaacs's description provides a foundation on which to find solutions to the continuing exclusion of young people with learning disability. In his paper on *Disability and the Education of Persons* Isaacs rejects special education's restrictive ontology of personhood. He calls for a more complete account where aspiration and human flourishing provide an ethical framework towards true student centred education provision. Jarman (2008) suggests that a feminist ethic of care complements an education approach where emotionality, mutuality and interdependency are promoted. These approaches will help resist what Roger Slee describes as the "collective indifference" that restricts the opportunities for young people with learning disability to realise a good life. The recognition that through our interdependency we can all begin to collectively determine the course of our life takes is an important realisation.

If we wish to support children and families in ways that will enhance well-being for all in our communities then we should work from an alternative position that imagines people as interdependent and that sees the wider sharing of all resources as the basis for a more democratic and just society (Ballard, 2007).

Belonging

The narratives of the young people with learning disability clearly reflected a desire to find a sense of belonging in school and the wider community. Their discussions in the focus groups were full of wanting to be accepted for who they are. Perhaps being accepted for who they are defines the distinction between mere participation and belonging. A sense of belonging can be found through connecting with people with and without disability in schools, tertiary institutions and workplaces, or by enjoying leisure and recreation with the community. Importantly, they wanted to experience these things alongside people who were not family members or paid support workers. The reality was the young people in our study rarely got the opportunity and were excluded as a result.

Belonging is central to one's emotional well-being (Osterman, 2000). One of the main effects of exclusion is the psychological impact resulting from a lack of a sense of belonging (Falvey & Givner, 2005). A sense of belonging includes experiencing support and greater control over one's life (Biklen 1985). Osterman in an extensive study found that a sense of belonging

is vital to one's sense of purpose, worth and value and directly impacts behaviour, well-being and identity. She found in her study that many students failed to find a sense of belonging in schools and this often resulted in feelings of anxiety and low confidence. Additionally, finding a sense of belonging in a special school is problematic as although the students may feel they belong to that institution they will have very little if any contact with other school communities. This naturally acts against finding a sense of belonging in secondary schools and by definition the wider community. Causton-Theoharis and Theoharis (2008) argue that creating a sense of belonging requires more than access to the mainstream classroom. Our findings support this in promoting attitudes and the type of support offered as significant in whether the young person feels they belong. In Chapters 5 and 6 the students with learning disability described negative experiences in the secondary schools with some evidence of verbal bullying. They felt marginalised from the wider school community and as a result had very little contact. The general disconnect students with learning disability felt from the mainstream of secondary schools has important implications for how school units and learning support classes are included or not. This supports the requirement for a whole-school approach to establish confidence in the school community regarding inclusion. I describe and provide recommendations for a whole-school approach to enhance a sense of belonging at the end of this chapter. A whole-school approach can provide a sense of belonging where diversity is the default position and not an afterthought (Wedell, 2008). A whole-school approach can be found in what Noddings (1995) describes as an ethic of care that resists the drive for competitive individualism in schools.

In this way the concept of inclusion as a whole-school approach needs to move beyond technist assimilation or mainstreaming by special education policy rhetoric and a service systems approach (Slee, 2001b) to embrace a sense of belonging as the moral obligation of all. Therefore an inclusive school is a school where everyone is accepted and belongs (Pearpoint, Forest & Snow, 1992; Stainback, Stainback & Ayres, 1996).

The black feminist writer bell hooks in her book *Belonging* (2009) describes capitalist society's individualism, narcissism and indifference as a key barrier to gaining a sense of belonging. She blames the dominant ideology of liberal individualism, which perpetuates imperialist white supremacist capitalist patriarchy. hooks's notion of belonging is defined as a culture of place and is founded on the reciprocal connection between humans. hooks further

defines belonging as feeling comfortable and gaining safeness in the local community while acknowledging the diversity of all human life and the need to care for people and the place wherever that may be. This then allows us to rethink belonging in terms of communities of moral, affective and caring relations rather than communities of stable, fixed identities.

Hall (2010, p. 50) in an article on social inclusion and belonging relating to people with learning disability, draws on the work of Bauman to define the social inclusion/exclusion conundrum. She writes:

Bauman (1998) goes so far as to say that social inclusion is an exercise in “normative boundary setting,” where what is acceptable, moral, independent and competitive, is separated (by the clear line, as noted above) from what is unacceptable, immoral, dependent and non-competitive. To be socially excluded therefore is to be an exception, to be deviant from the “universe of moral obligation” (Bauman, 1998, p. 77).

Hall (2010) provides a definition of belonging as a counter-narrative to this barren moral position described by Bauman: “To belong is to feel attached, to feel valued, and to have a sense of insidership and proximity to “majority” people, activities, networks and spaces” (p. 57). Gleeson in his article *Geographies of disability* (1999) concluded that societies should re-imagine and re-create their cultural, political and physical structures so that people with learning disability experience a genuine sense of belonging. This throws out a challenge to inclusive and special education policy and practice that “speaks” of inclusion without the acknowledgment that a cultural shift towards a whole-school approach is required.

The narratives of the young people with learning disability in our study described the experience of community-based support through living with their families and mostly attending vocational day services and discrete social clubs which has all been in the community, but mostly out of sight and not belonging (Hall, 2010). One of the student participants Susan described powerfully her inner struggles with wanting to be included at the youth club but not having the confidence to attend. Instead she just looked as a “stranger” from across the road. Hall (2010) considers people with learning disability continue to suffer from the historical and cultural influences of being understood as other and as abject, and potentially dangerous to the social order, “as needing to be separated out and bounded, in short designated as not belonging” (p. 52).

Purpose

What makes us get out of bed in the morning? For many people getting out of bed is more about compliance in that we need to go to school or work. However, we also need some internal drive and motivation founded on what we are passionate about. Having a sense of purpose in our lives is critical in finding contentment and fulfilment. If we do not then perhaps life can just pass us by or we just go through the motions so to speak. We need to become the authors of our own life story through our relationships with others. I contend it is through our relative interdependency we find purpose in our lives and a way to realise our dreams, our purpose and passions. The young people with learning disability in our study were able to express a purpose in their lives through their goals, aspirations and interpretations of their experiences. Their friends and family provided a strong sense of purpose in life through supportive and loving relationships. They saw relationships as critical in providing a purpose in their search for a good life. Although gaining material things was a goal for most young people it was friends, family and people in general who they cared about and “lived for.” They communicated about the purpose of going to college and work in order to do the things they want in life but it was the empathy, concern and care for others that came through strongly in the findings chapters.

Reason

Young people with learning disability have often been perceived as having impaired or flawed reasoning (Johnson, Walmsley with Wolfe, 2010). Indeed, young people with learning disability have been seen as a homogeneous group or subsumed within generic disability labels. I consider this does great disservice to each individual so labelled. I suggest we need to consider each individual and what they consider a good life, recognising that it will emerge in relation with others. The strong voice and deep insights provided by the young people with learning disability regarding their lives have demonstrated they are well capable of reasoning if provided the opportunity and context. The powerful comments of all research participants have provided a stepping stone to their inner lives. The relationships developed through the research process by Andrew, Caroline and I have allowed for a deeper mutual understanding. Mutual understanding that will help us all in our individual and collective search for a good life.

Capabilities

A capabilities approach is a human rights informed theory that challenges orthodox neoliberal ideologies based on the market and economic consumption (Nussbaum, 1992, 2000, 2003, 2006). As Carpenter (2009, p. 354) articulates in his article it has the potential to provide a holistic framework for integrating education and social policy and broad human rights. Interestingly, Burchardt (2004) argues that the social model's distinction between disability and impairment as a socially constructed discriminatory process has similarities to a capabilities approach. A characteristic feature of the capabilities approach is an insistence that civil freedoms, democracy, social opportunities and equalities are interdependent. A capabilities approach moves away from economic and utilitarian measures that do not account for peoples differing needs. It also has the potential to move beyond student-centred and individualised planning that focuses only on material goods and services to areas such as emotions and spirituality (Johnson, Walmsley with Wolfe, 2010, p.127).

I suggest that a focus on the young people's capabilities by policymakers when considering inclusive policy in New Zealand would shift the context from individual forms of support to more collaborative. A capabilities approach can provide a benchmark to gauge the journey towards a good life for young people with learning disability. The capabilities approach opens up issues related to judging human progress, reconciling liberty and justice, and how to take account of the requirement for social justice. As Bauman (2008) contends like Sen (1992), economic growth and consumer consumption are not sufficient markers to judge progress towards a good life. It follows then that education and social policy driven by the rhetoric of competitive individualism are not enough to ensure human progress. Sen (1992) emphasises the need for freedom and where equality and social justice requires social and political intervention. In this way a capabilities approach acknowledges that people are not equally positioned to realise their human capabilities such as young people with learning disability.

A capabilities approach is useful in moving education policy in New Zealand from issues concerning a limited view of a good life as independence, choice presence and participation, achieved only through resource allocation, skill enhancement and competition. A capabilities approach might encourage a more comprehensive adoption of exclusion/inclusion measures.

Social and economic indicators through a capabilities approach allow for a more comprehensive picture to emerge. The adoption of a capabilities approach as an evaluative framework by the Equality and Human Rights Commission in the UK (2007) is a good example of its application. Importantly, collaboration is required between state, employers, communities and citizens. This will necessitate perhaps the acceptance that there might be an economic or/and social cost worth paying where some people are favoured over others to achieve social transformation and a more just and fair society (Burchardt, 2008; Carpenter, 2009; Nussbaum, 2000, 2006; Sen, 1999). In addition taking into account for example the emotional aspects of the young people's lives would allow for a more nuanced view of the person's life and how best to provide support.

In this thesis I have suggested that in relation to the search for a good life the young people with learning disability actively sought their rights and the responsibilities that come with them. In addition they wanted the opportunity to take responsibility for their lives. In the next sections I now consider how rights and responsibilities, opportunities and contributions are important elements to consider at both the policy and practice level.

Rights and responsibilities, opportunities and contributions

In policy

This thesis supports the proposition that educational policymaking is characterised by the dilemma of a struggle with economic, ideological, political and social considerations (Barton & Tomlinson, 1984; Fulcher, 1989). Arguably, written policy exerts discursive governmentality (Foucault, 1979) over the context of how it translates into practice, as it sets the discursive contours within which policy context is taking place. The intricacies of power are endemic in the policymaking process and its evolving nature through time, as various social actors attempt to exert their influence and safeguard their particular interests. I suggest this precarious process can be seen in New Zealand's inclusive and special education policy contradictions. The requirement for a transparent critical examination of this policy, in line with a capabilities approach, is timely so that a viable solution can be found to the continuing exclusion of some students. This might allow us to fully understand the political and

contentious nature of education policy, learning disability, special education and inclusion in order for us to move forward with clarity of purpose.

In relation to the education review process the focus by ERO on how well students with high needs are doing under *Success for All – Every School, Every Child* is limited, as they allude to themselves, when considering older secondary age students transitioning to post school life. The significant majority of schools reviewed were primary and therefore little useful data is provided in relation to post school outcomes or achievement. Indeed, ERO highlight that few schools of any type reported on achievement for students with “special needs” let alone secondary schools. Interestingly, the recent report *Including Students with High Needs: Primary Schools* (July, 2013) curiously as the title conveys, only deals with primary schools; secondary schools are not considered. I believe this is because as ERO have mentioned in earlier reports on high needs students it is less easy. How inclusive schools are in relation to their career and transition processes is therefore not examined in any significant way. There is a clear mandate for this to happen under the umbrella of ERO’s review on “how well secondary schools are preparing all senior students for further education, training and employment” (ERO, 2012). ERO’s follow-up reports in June and September 2012 regarding the school self-review questionnaire highlights staff consider students with high needs are best educated full-time in special units. All this emphasises how few secondary schools are evaluated and how far away from a whole-school approach they are in relation to students with learning disability. Indeed the latest report of this series in July 2013 appears to have put secondary schools in the too difficult basket as it only reports on Primary Schools (ERO, 2013).

The resounding silence of the voice of students with learning disability from the EEL longitudinal research programme on transitions from school for youth is an example of how they are denied the opportunity to make the contribution they desire. Their opportunities are restricted because they do not feature explicitly in policy work related to careers education and the ongoing review of CIAGE. I contend policy has positioned them as not requiring a “career” which therefore restricts their opportunities for further education, training and employment and this restricts their likelihood of finding a sense of belonging in the wider community. This situation is best understood in the context of low expectations, attitudes and how we value young people with learning disability and their contribution.

The guidance relating to transition targeted for “special educators” and schools as in the National Transition Guidelines recently promulgated by the MoE (2012) missed an opportunity to promote a focus on a whole-school approach. The guidelines do little to address the concerns highlighted in Chapter 6 regarding how it reinforces notions that only special educators can work effectively with these students in supporting the transition process. This again acts to abdicate secondary schools responsibility for these students particularly the leadership of schools and career departments which our research study findings demonstrate. It was also my experience as manager of LSTS. In addition I consider there is a requirement for professional development to support the guidance otherwise it will not influence practice in schools and student outcomes. There is a requirement for a cultural shift in schools that will raise expectations and attitudes for students with learning disability. Policy and indeed legislation must address the significant and enduring lack of pathways for students with learning disability. Findings suggest tertiary opportunities are very limited (O’Connor et al., 2012) and do little but perpetuate discrete courses that lead from school into discrete courses within tertiary and most often lead directly into a vocational day service on completion provided a place is available. Pathways into university should be available to students with learning disability to further their learning but importantly to further opportunities for social, living and leisure opportunities with their peers without disability (O’Connor et al., 2012). Likewise meaningful paid employment is mostly a pipedream with current policy work doing little to change that perception for young people with learning disability.

In practice

Neoliberal approaches to education and social welfare place individual rationalities like choice as central to education and social welfare service provision and presume that increased choice equals better outcomes. The findings in our study demonstrate this is not so and is supported in research by (McClimens & Hyde 2012). It makes no sense to frame provision on this basis because if young people with learning disability were completely and fully independent in their choice-making then they wouldn’t be receiving support under the control and management of special education and vocational service systems in the first place. Equally, the opportunity to make choices is more about who frames and controls those

choices. A student with learning disability might choose tertiary study but if there are no courses available there is no valid choice.

Indeed in this thesis I have problematised neoliberal conceptions that position choice and independence as supportive of the universal human rights of people with learning disability. My claim is that none of us are independent in the presumptions of such conceptions and ideologies and instead I view we are all fundamentally interdependent. Therefore the recognition of our relative interdependency is where we should begin our search for a good life.

Rights across many Western countries for young people with learning disability have portrayed them as “adults-in-waiting” (Ball, Maguire & Macrae 2000; Wyn & White 1997) or in terms of the charitable, economic and constitutional rights of deinstitutionalisation and community care (Johnson & Walmsley with Wolfe, 2010; Wolfensberger et al., 1992). Findings in our study have shown the translation of policy rhetoric into action that results in meaningful change in the lives of young people with learning disability remains at the very best elusive. Their rights are mostly defined by their role as special education and social welfare service consumers. I argue this leads to unrealised lives and makes their search for a good life more difficult. Andrew and Caroline and the study participants have demonstrated their capacity to make important decisions through the research process. This is relevant as most choice for these young people is premised on the mundane i.e. what to wear or drink.

Rights come with responsibilities. There was a real sense from the findings these young people wanted to take responsibility for their lives as part of a desire to live their lives. Rights go hand in hand with responsibilities. If a person has the right to work, that person also has a responsibility to grasp that opportunity. Rights then bring responsibilities but only if the opportunity is there to begin with. Opportunities in liquid-modern, neoliberal times in New Zealand present particular challenges for young people who are positioned as *flawed consumers*. The participants demonstrated on a number of levels the desire to take responsibility for their lives and the lives of others. They were able to articulate in their comments a responsibility for themselves as a crucial stage in understanding the self as positive and worthy. In order to be responsible as citizens one needs to be responsible for self

first. This is important in the sense that it acknowledges that we all require a sense of ourselves as people with unique desires, goals and aspirations for the kind of life we want. This leads us then to interact with others and form reciprocal trusting relationships.

The enduring responsibility communicated in the comments towards family members and friends by the participants was a particular feature of the findings in our study (Chapter 5). The participants also expressed a desire to be responsible for the wider community in which they lived. However, the reality was they existed at its margins and this sense of responsibility did not appear to be reciprocated as demonstrated by some of the participants negative interactions with the wider community reported in Chapter 5.

This desire for responsibility through open paid employment goes against the history of learning disability where they have been mostly absolved of responsibility to actively support themselves. Historically, perceived as passive recipients of support, a desire for economic and social responsibility is not often assigned to people with learning disability. The participants in this study clearly want to contribute positively to the community in which they live but rarely get the opportunity to do so in a way that values their capabilities. Their contribution is largely managed by specialist education and social welfare services. An important aspect for the participants becomes how they can realise their desire to make a positive contribution in their journey towards a good life within a landscape that seeks to control and manage them along a restrictive post school pathway they mostly do not want.

Foucault (1978) argued that power is not possible without knowledge. By providing young people with learning disability with more information, they are more likely to be able to resist the influence of other people's power and make meaningful choices about their futures. Without increased knowledge, people with disability only consider a limited range of options and do not question that they have fewer choices than young people without disability (Ward et al. 2003b). This helps to maintain young people with learning disability in a subordinated social position.

The balance between freedom and constraint

Bauman and others Ballard (2004) and Slee (2011) view the interplay between freedom and constraint as important in determining a socially just, moral and democratic society. The

balance between freedom and constraint is important for education. Bauman views freedom as a relation of power. Freedom within the research team was managed by the trust, empathy and compassion we had for each other which over time began to equalise the power dynamic. The young people with learning disability wanted the freedom but were constrained by their lack of opportunity as a result of not being valued, often being positioned as incapable of contributing and not responsible because of being viewed as incompetent and in need of support.

The young people in our study wanted the freedom and opportunity to be recognised for who they are. Equally, they wanted to do many of the things that any young person wants such as go to college, get a job, have enduring relationships and feel they belong in the community with people they can relate with. Solutions can only come from education and society in general and not through special education or social welfare service solutions.

Change, career and transitions

Change can be seen as an inevitable part of life in this complex, consumptive, fluid life we live today. Coping with change is not easy for anybody but I would argue is more difficult for young people with learning disability who might also be said to lead largely predictable lives in comparison to young people without disability. Predictable lives in the sense the lives of young people with learning disability are largely decided by other people and mostly provides a restrictive pathway from special education services to social welfare services. This places huge responsibility on those staff to have clarity of understanding both theoretically, practically and emotionally to ensure they best support young people with learning disability and their families as they transition from school in the search for a good life. I have no doubt that the vast majority of staff who support young people with learning disability and their families in school and in the community have their best interests to the fore. However, the clear voice of the young people with learning disability in our study demonstrates that their transition experiences do not provide them with the life they say they want. They do not enter tertiary study that leads to paid employment and have limited involvement in the wider community. They appear to remain mostly at the margins of society as a commodity traded by the special education and social welfare industries.

In Chapter 2 I described life as episodic and full of transitions focusing on the transition from school to post school life. Importantly, transition is understood as a process and not an event. The transition to post school life is one of many we all make in our lives and is particularly challenging for all young people as they seek an identity in today's liquid modern society. I have argued that young people with learning disability largely follow a parallel transition process to most other young people. I have suggested it is a restrictive pathway that is signaled early in secondary education under the control and management of special education services. This restrictive pathway leading to a vocational service day centre must close and alternative pathways that are flexible and lead into further education, training and employment must be opened up. Special education services must stop managing and controlling transition pathways for young people with learning disability. They must work in partnership with career services in schools and Careers NZ so that attitudes and expectations are changed and raised through whole-school approaches.

Through my research journey with Andrew and Caroline I have come to see the exclusionary influence that the language of special education has had. It is time now to consider the word "transition" because I consider it perpetuates "special" thinking and expectations for "special" young people. We now need to use phrases like "career pathways" and "flexible pathways" alongside when working with young people with learning disability so that career services in schools and outside include all students and young people in their work.

In the previous sections I have discussed the key elements in the relational dimension that I believe need to be considered in how young people with learning disability and indeed all people can journey towards a good life. We need to consider all these elements together as they overlap and interact with each other. This holistic conception of the relational dimension positions a good life as relevant for all people including young people with learning disability.

A way forward: A “whole-school” approach to career and transition education

Research question discussed:

- How can the views and perspectives of young people with learning disability inform inclusive and special education policy and practice?

Student participant (Stephen): *I like life and opportunities and those who share it with me because that's how life should be.*

Stephen's words have deep insight and convey his overwhelming optimism and desire to live his life in relation to others. The words convey his hopes for the future in a life shared with others and opportunities abound. For his hopes and the hopes of other young people with learning disability the time for a special education response in their transition from school must end. Special education policy and bureaucracy has deeply failed these young people and their aspirations for a good life. It is time for a relational, interdependent and collaborative approach.

Neoliberal influenced education policy in New Zealand has created an environment where special education and social welfare service provision maintains control over post school outcomes for young people with learning disability. This is achieved through setting the ideological and financial context for policy work to a generic disability group and in isolation from mainstream secondary education structures despite the rhetoric of inclusive policy (MoE, 2011). This has the effect of promoting an expectation that students with learning disability are under the control and management of special education services only. The expectation then becomes the well-worn path into a vocational service day provision that, despite current work such as *Enabling Good Lives* (Office for Disability Issues, 2011), leads to unrealised lives. Education policy bureaucrats and school leaders must view students with learning disability as capable and competent members of schools who must experience the “common condition of education” (Humber, 2014, p. 287). This requires a whole-school approach where everyone has a career and an expectation of a pathway into tertiary study and/or paid employment that is embedded in holistic planning for these students. This would

be known as “career planning” and no longer transition planning supported only by special education professionals or social welfare service staff as is usual for students with learning disability. In contrast to the current situation, a whole-school approach is about career specialists working with all students including those with learning disability. This requires a close working relationship between career staff and special education professionals and Careers New Zealand as the government contracted service to provide career education for all.

Schools need to consider the programmes currently available to them that can provide effective models of inclusive practice. These programmes like the Young Enterprise Scheme (see Gladstone, 2005) and Project Search have the utility to make inclusion a reality. If we are to find solutions to the continuing exclusion of young people with learning disability we must move away from policy and practice that perpetuates an individualised response and embrace true collaboration.

I argue the dilemma of the “expert” or “special educator” in the education of students with learning disability can be mitigated through the relational dimension where all professionals collaborate to effectively support the students with learning disability during the transition from school. The transition literature calls for collaboration as a crucial element in seeking effective transitions (Dee, 2006; Kohler & Field, 2003; Mirfin-Veitch, 2003; Smith & Routel, 2010). This means that the career specialist must work closely with the special education professional in schools in relation to students with learning disability. The findings in this study would suggest this is not the case. ERO’s (2012a, 2012b) findings concerning students with High Needs under *Success for All – Every School, Every Child* demonstrates that few schools reported on achievement for these students. ERO also reported the leadership in many schools didn’t have a good understanding of who their special needs students were let alone reporting on their educational achievement. This indicates a lack of whole-school approach regarding these students. This reinforces the requirement for effective collaboration among professionals in schools to ensure this happens.

Kearney and Kane (2006) in the New Zealand context use a quote from Stainback et al. (1996, p. 36) to define inclusive schools as “places where everyone belongs, is accepted and is supported by his or her peers and other members of the school community in the course of

having his or her educational needs met.” The value of inclusive schools as one where all its students can find a sense of belonging and realise their goals and aspirations is relevant as an important component of the relational dimension in this thesis. In this way understandings of inclusion are strongly related to social, political and cultural contexts (Booth, 1996; Kearney & Kane, 2006; Slee, 2001b).

There was some evidence from our research findings of a lack of collaboration by staff in regard to students with learning disability. The findings in our study suggest there is little contact or collaboration between CIAGE staff, SENCO’s and staff in special schools or learning support and special units in secondary schools. Good career planning processes are relevant for all students. This is an important point as it acknowledges the requirement for one effective career planning process that embraces all students. Students with learning disability must benefit from the new CIAGE framework and resources recently developed as with the *Career Education Benchmarks* (Careers NZ, 2012). Schools must encourage their career specialists to work alongside students with learning disability and specialist staff in developing career plans and pathways.

Inclusive policy

Arguably inclusive education policy has made no difference since Special Education 2000 in the lives of young people with learning disability as they transition from school in their search for a good life. Inclusive education policy must include young people with learning disability in major programmes of work like the *Youth Guarantee*. Pre-foundation and pre-vocational access courses must be provided and formalised so that young people with learning disability can begin to benefit from further education and training in a tertiary environment with all its social, educational and economic benefits. The range of courses and crucially pathways into, through and beyond tertiary study must be addressed by the MoE and its tertiary sector.

Future major research programmes on careers and transition that influence policy such as the EEL programme should include young people with disability as a moral and democratic imperative. No longer can every marginalised group be considered except young people with learning disability or indeed the wider disability group. Policymaking must be connected and

not fragmented to resist young people with learning disability being seen as requiring only specialist interventions outside and separate to those for other young people. In policy work young people with learning disability should be promoted as requiring a career pathway and not to transition along pseudo-vocational pathways into specialist service provision.

A consortium approach by schools

If relationships are so important it makes good sense for schools to explore collaboratively how this might benefit all students, particularly those with learning disability. Clusters of schools developing close relationships with each other allows for innovation and new opportunities to be created. As described in the findings chapters there were very limited tertiary course opportunities. Often schools do not have the student numbers or staffing to support their students with learning disability to benefit from tertiary opportunities if they were available. By schools working together they can maximise opportunities through a consortium approach. As an example one school in isolation might only have one or two students who have a particular interest in an area for tertiary study. By a group of schools working together they could generate enough student numbers for a course to be developed and run by a local tertiary provider. Any support required for the students to ensure their learning and achievement can be provided by the schools pooling their resources.

The inclusive confident school

The quality of a school's leadership has a profound influence on whether schools can be "inclusive confident" (ERO, 2010, 2012a, 2012b; Ministry of Education, 2010a). Extending the notion of school leadership from hierarchical to distributive forms of educational leadership in schools as for example with the Teacher Leadership movement in the UK have the potential to transform schools to reflect and enact an inclusive culture and values (see: Frost & Durrant, 2002; Macbeath & Moos, 2004)). Principals and senior managers focusing only on hierarchical forms of leadership have the potential to stifle teacher innovation (Frost, 2007). Teacher Leadership recognises that all teachers are leaders of educational transformation. I consider this to mean that all teachers can collaborate as leaders of inclusive learning and teaching and have the power to expose, challenge and reject exclusion while embracing democratic values and practices.

The government target under the work programme *Success for All – Every School, Every Child* (2010b) for 100% of schools to demonstrate they are “inclusive confident” is in my opinion flawed. There has been little valid exploration of how secondary schools demonstrate this in comparison to primary schools as I suggest there are crucial differences which ERO acknowledge in their reports (ERO, 2010, 2012). ERO now appears to focus on primary schools (ERO, 2013) because as ERO admits it is easier. It also conveniently overlooks the presence of special schools in New Zealand and how they might demonstrate they are fully inclusive?

Freedom and authentic choice are important elements in a democratic society but a degree of constraint is required with that choice to mediate a society that we want to live in and where all people have equity of opportunity. I propose an alternative to the individualised, competitive market model that might be found in what Ballard (2004) advocates for as a collective model which I interpret as being found in the relational dimension and in the need for the relational school. The relational school has certain identifying features when a whole-school approach is adopted and it can be viewed as “inclusive confident.” In this way schools can be places of educational transformation where a pedagogy of hope (Van Hove et al., 2012), a pedagogy of listening (Macartney, 2012) and an ethic of care (Noddings, 1995) are embedded. There are a number of distinguishing features that define a whole-school approach and some are listed in Table 11 below. The list is just a starting point for schools and must be added to and developed.

- All students consider they belong in the school
- All students are considered as capable, responsible and contributing
- All students are seen as people first who learn and not learners who acquire marketable skills
- School leadership demonstrates values of social justice, equity and democracy
- All staff are valued and acknowledged for their individual and collective contribution towards being inclusive confident
- All teachers are considered and supported to be leaders of inclusive teaching and learning
- All teachers are supported to be practitioner researchers and lifelong learners
- The relational school develops partnerships with other schools to maximise opportunities for all students through a consortium approach that shares values, planning, resources and expertise

Table 11: Features of the relational school

The inclusive confident teacher

“No pedagogy which is truly liberating can remain distant from the oppressed by treating them as unfortunates and by presenting for their emulation models from among the oppressors. The oppressed must be their own example in the struggle for their redemption (Freire, 1970, p. 54).”

What I have learnt through the relationship with Andrew, Caroline and young people with learning disability through this research journey has profoundly impacted me as a human being and as a teacher and practitioner researcher. In this section I describe the elements of an inclusive confident teacher. Fraser (2000) describes the effective teacher who recognises and responds to “underlying power dynamics” and so is able to “welcome and include all students, parents and families” (p.120). MacArthur (2009) suggests that teachers are effective

when they see students as active and capable. Teachers are an essential foundation in the process of building sustainable democratic schools and societies.

Actively altering the power relations paves the way for making a different kind of engagement possible between the teacher and student. Nodding (1992, 2003) in respect of the difference between effectiveness and excellence in teaching promotes the relational account of the practice. There is a focus on care and trust on the part of the teacher and the development of an abiding sense of responsibility towards the student's future that ought to be an integral and distinct internal good of a school's professional practice. A teacher's intellectual curiosity in maintaining this relationship is also a virtue to be cultivated and extended. There is a notion here that to be excellent does require important technical skills, but there is something fundamentally moral and ethical about the way in which they are developed, deployed, evaluated and come to embody a teacher's character. Virtues of reciprocity are seen as qualities of creating trust and risk while exercising care and compassion in an authentic, non-manipulative relationship (Noddings, 2003). These understandings can provide a foundation for building inclusive confident teachers.

Working within a DSE framework inclusive confident teachers do not only require fixed amounts of knowledge, skills or behaviours to be successful. What they require is to be responsive to the changing nature of the communities in which they work and be open to continuous reflection and adaptation (Allan, 2012). Whether a teacher is considered to be inclusive confident should be about risk, honesty and transparency. A desire to be an agent of inclusive dialogue where the Other feels they belong. An ethic of care demands an absolute responsibility to the Other and the relationship is experienced, because of an inadequacy in the face of the Other, as asymmetrical being disturbed by the obligation of the Other is a vital part of what it is to be human and I suggest an inclusive confident teacher.

Exploring deeper the inclusive confident teacher must practice pedagogical freedom (Freire, 1998). In order to educate for freedom teachers must challenge how everybody involved understands the pedagogical process particularly the students. Fundamentally this is about accepting that all students can act capably and responsibly if provided the right learning environment. This naturally requires taking risks in the interactions and ensuring that both teachers and students have recognised and can exercise power. This happens in the relational

dimension where a shared dialogical space creates care, curiosity, hope and listening. In this way the power of the inclusive confident teacher is in the power of the learning process created as a community of practice where all can share their personal narratives. A shared dialogical space encourages us to cross boundaries that may exist because of race, gender, class, professional power as well as disability.

Language has a vital part to play in the inclusive confident teacher. Critical feminist thinking on issues of difference and voice challenge us as teachers to recognise the voices of those students that are marginalised and silenced. These voices will communicate in different ways and therefore we must be attentive and make a space. This might mean we make a space for silences as well as voices to subvert that culture of neoliberal frenzy and competitive consumption that demands all desires be satisfied immediately. The ultimate goal for the inclusive confident teacher becomes creating a democratic learning environment where everyone feels a responsibility to contribute towards pedagogical transformation.

Inclusive confident leadership

Leadership and inclusion do not always sit easily with each other, particularly in a neoliberal individualised and competitive education marketplace that schools find themselves in today. The notion and success of inclusive confident leadership lies in promoting forms of distributive leadership. Traditional forms of leadership based on managerialism (Foucault, 1978) for example exclude members of the school community in the hierarchical relationships that are promoted between the managers and others. Power is invested with particular individuals in particular positions. In this model those not in management positions will usually have little say in the decision-making processes. This acts against inclusive confident teachers because it allocates individual responsibility rather than collective responsibility.

Inclusive confident forms of leadership reject hierarchies that promote bureaucratic forms of organisation that generally reflect a masculine, corporate position. Inclusive confident forms of leadership promote equitable, horizontal relationships. Decisions are not made by individuals rather they are made collectively. Inclusive leadership is seen in a socio-cultural context where influence is more than the product of an individual. Inclusive leadership

promotes whole-school staff working together in their different roles and ways, maximising resources and creating a collective enterprise that champions diversity with excellence. Inclusive leaders engage in promoting inclusion, developing critical consciousness, supporting dialogue, enhances collective responsibility, adopt inclusive school policy and puts student diversity at the core.

Co-researching with young people with learning disability

Dissemination is an issue within learning disability research with the usual route through peer review journal publication. How research reaches teachers and related professionals is critical for raising expectations and changing attitudes concerning the capabilities of young people with learning disability. Andrew, Caroline and I are currently collaborating on a co-authored paper but we disseminated widely through delivering lectures to teachers and other professionals, numerous conference presentations both nationally and internationally and parent and support staff workshops and seminars. Teachers and other professionals do not usually read academic journals. After all, the research was about promoting Andrew and Caroline as experts regarding the lives of young people with learning disability and how to best support them in their search for a good life.

Through an exploration of the relational dimension and the interactions and dynamics of the research team a number of factors are now tentatively presented that might form the basis of good practice recommendations when involving young people with learning disability as co-researchers within a research team.

- Co-researchers with learning disability should be involved from the beginning of the project.
- Co-researchers with learning disability should be engaged on a contract as research assistants by the supporting university or funding body.
- Co-researchers with learning disability should be paid for their time involved in the project.
- It should be ongoing and be non-tokenistic.
- Co-researchers with learning disability should have a period of induction at the beginning of a project.
- Co-researchers with learning disability and non-disabled co-researchers must have agreed roles and responsibilities within the team that promote individual strengths and leadership.
- Co-researchers with learning disability have the opportunity for ongoing development of skills and knowledge through targeted training.
- The research team approach must alter and equalise the power dynamics over time with co-researchers with learning disability and non-disabled researchers.
- The research process must carefully consider what happens to the co-researchers with learning disability after the project ends and support their pathways.
- The relationship between research team members must be professional but needs to recognise the personal, social and emotional investment in working as co-researchers.

Table 10: Suggested guidelines for involving people with learning disability as co-researchers

Suggestions for future research and recommendations

The limitations of our study

Firstly, it is important to recognise the limitations of our and any research study. This is a small-scale study focusing on the perspectives and lived experiences of a particular group of young people with learning disability. The small number of participants provided for an in-depth exploration of these young people's experiences. Involving young people with learning disability as co-researchers in the research team allowed for rich data collection and analysis as well as ongoing member checking and presentation of findings through the research process. My role as an experienced teacher, practitioner researcher and my experiences as manager of the LSTS provided for a deeper relationship with all research participants and to better consider the wider implications of what the young people were communicating regarding their search for a good life.

However, because of the small number of participants it should only be viewed as a window into the social construction of learning disability. The views of the participants are not easily generalisable. Importantly, our study does not "speak" or represent the voices of other young people with learning disability or others with disability. I accept the research team members Andrew, Caroline and I have particular understandings, interpretations and ways of collaborating that would have been different with other people forming the research team. In deliberately focusing on the views and perspectives of a particular group of young people with learning disability I acknowledge there are multiple realities. The views of others involved in the transition process such as other students, parents, teachers and other professionals would have provided different findings.

Future research

In New Zealand there is policy, legislation, international human rights agreements, research and pedagogical frameworks that rejects exclusion and supports inclusive education. However, these frameworks need strong relationships and collaborations from all parties involved in order to move us all forward in our search for a good life. Inclusive education must be more than just about addressing the exclusion of labelled students (Ballard, 2003;

Slee, 2003). Policymakers, MoE officials, school leadership, teachers and others must recognise, challenge and reject exclusion at all levels and in all forms (Freire, 1997, 1998; Slee, 2001). They must value diverse ways of knowing, and acknowledge the potential of different realities and perspectives to inform inclusive policy and practice.

In order to recognise, challenge and reject negative assumptions we need to focus on creating and sustaining relationships and attend to moral-social-political-cultural processes and structures. Research methodologies need to be collaborative and work reflexively to explore influences at the macro and micro level. PAR research must listen to and with participants, rather than listening for evidence of preconceived theories (Lather, 2003; Thomas & Loxley, 2001).

In the journey towards an inclusive education system and society (Ministry of Health, 2001) there needs to be more qualitative research undertaken in direct, meaningful and extended collaboration with young people with learning disability in leadership roles. Future research endeavours must recognise the personal, emotional and professional commitment required in these collaborative forms of research over extended periods. In addition to consider the implications beyond the ending of research studies (Northway, 2000).

The MoE research Teaching and Learning Research Initiative (TLRI) scheme is a major research vehicle in New Zealand. I strongly suggest the TLRI should fund collaborative, disability studies in education research. Since its inception in 2003 the TLRI has funded 119 research projects in education. Not one has been related to students with disability or special education needs. This appears a contradiction to the MoE's goal to create a fully inclusive education system (MoE, 2010a) and its mantra of best evidence research informing policy and practice.

More honesty leads to innovation

The discourse of parent choice as promulgated by the MoE is a false one and is contingent on who controls the definition of that choice (Smith & Routel, 2010). This has masked the fact that the MoE continues to support the provision of segregated, "special" education placements and interventions for students with disability (Millar & Morton, 2007; Slee, 2010). As I and others have suggested, special schools and special education are stronger and

more resilient now than they have ever been in New Zealand (McMenamin, 2011, 2014). Therefore as highlighted in our study the language, practice and structures of special education continues to allow the mainstream of education to abdicate its responsibility for students with learning disability and others at the margins of the system. Rather than parallel processes special and mainstream education processes must blend as one so that all students are viewed as requiring a career pathway.

Recognising the social construction of young people with learning disability's identities can pave the way for new and innovative practices in both schools and teacher education. In schools the recognition of new and capable identities for students with learning disability will encourage teachers to be leaders of educational transformation through their practice so that schools are places where all students are included and feel they belong. In teacher education young people with learning disability like Andrew and Caroline can work in partnership with teacher educators as mentors and contracted tutors to develop authentic knowledge for delivery to future teachers so they can understand and benefit from the lived experiences of the young people they will work with. This will support alternative designs and delivery of teacher education courses that currently focus on preparing teachers to develop the special education knowledge and skills assumed to be required to work with "special" students. In this way teacher educators and the future teachers of tomorrow can be leaders of inclusive teaching and learning.

Importantly, for young people with learning disability to realise their goals and aspirations there is a requirement for research that supports practical solutions. There are vehicles of effective inclusive practice that can bridge the yawning gap between the rhetoric of policy and practice (Mittler, 2007). Both Project Search and the Young Enterprise Scheme as earlier described are well proven international programmes that research initiatives can be built around in order to provide best evidence. Funding research into the effectiveness of these programmes in the New Zealand context to provide meaningful pathways for young people with learning disability into tertiary education and sustained paid employment is valid and urgent.

Recommendations

Based on the findings in our study, the following recommendations are suggested.

Ministry of Education

- The MoE should support a project/demonstration of Project Search in New Zealand, in collaboration with other government departments and agencies, to create training to employment internship opportunities for students with High Needs in their last year at school.
- The MoE should take responsibility for tracking students with learning disability (both ORS and non ORS) well after they have left school to inform school career and transition planning and school review and development. A national survey on the post school pathways and destinations of students with High Needs would also be appropriate.
- The MoE should amend their document *National Transition Guidelines for specialist educators, schools and parents* to *National Career Guidelines for career educators, school leaders, staff and parents*.
- The MoE should ensure Careers New Zealand resources and advisory service are accessible, have relevance for and include students with High Needs, particularly their online career portfolio, benchmarks and career management competencies.
- The MoE should ensure ERO review and report on how well secondary and special schools are preparing students with High Needs for future education, training and employment.

Tertiary sector

- The MoE in collaboration with the tertiary sector should establish pre-vocational and pre-foundation pathways into, through and beyond tertiary education for students with High Needs in line with *Kia Orite, Achieving Equity* (2004a).

- The tertiary sector should provide a wider range of vocational course options and pathways into, through and beyond tertiary education for young people with learning disability that leads to sustained paid employment.
- There should be a project/demonstration by a university that explores the inclusive benefits for all in having students with learning disability access tertiary learning and campus life with all its opportunities for personal and collective growth.

Schools

Secondary schools should adopt a whole-school approach to working with students with learning disability in the transition from school by:

- Planning for the transition from school for students with learning disability should become known as “career planning” and no longer “transition planning.” There should be clear guidance on its relationship to the IEP process.
- All students with learning disability should have a generic “career portfolio” from Year 9 that contains planning, records and celebrates achievements. It will be formative and summative.
- The career specialist in secondary schools should be the lead professional in career planning with students with learning disability and their families as part of a collaborative, multi-agency approach.
- There should be a requirement for career specialists in schools to work directly with students with learning disability on career planning.
- School clusters and consortia should collaborate to maximise opportunities for their students with learning disability and lobby local tertiary providers on course provision and quality.
- Secondary schools should track the post school destinations of students with learning disability to inform their school self-review and development processes.

- School should use the Young Enterprise Scheme as a vehicle for effective inclusive practice among students with and without disability.

Research

- There is a requirement for a research study in New Zealand that designs, implements and evaluates the benefits of young people with learning disability as full-time, live-in tertiary students at polytechnic and at university.
- There is an urgent requirement for research that collaboratively explores further the factors that act to exclude young people with learning disability from realising the kind of life they want in contemporary society.
- There is a requirement for further research that considers innovative and collaborative methodologies in gaining the views and perspectives of students with disability. Further research that extends the design and use of the focus group instrument utilised in our study would be appropriate.
- Further research on collaborative methodologies that specifically focus on and explore the interdependency of research team members comprised of co-researchers with and without disabilities.
- Research that funds and promotes young people with learning disability on the academic conference circuit through training, preparation and presentation of their lived experiences.
- Research based evaluations should form an integral part in the hoped for implementation of the Project Search and Young Enterprise Scheme programmes.

Conclusion

In this thesis I have exposed, challenged and rejected the exclusionary landscape for young people with learning disability making the transition from school in their search for a good life. I have problematised the pervasive influence of neoliberal hegemony in education and

the effect on its most marginalised and vulnerable students. The marketisation and corporatisation of schools has created an environment that has encouraged an increasingly resilient special education service to flourish as a stinging contradiction to inclusive policy rhetoric. In this way special education policy and practice driven by bureaucracy and professional control has allowed the mainstream of education to abdicate its responsibility for students with learning disability at the margins of schools.

Education policy needs to tackle head on the contradictory imperatives arising from the inclusion, exclusion and special education conundrum. Collaboration rather than competition and interdependency rather than individualism among schools is required. Special education service provision needs to change from one that is founded on defining needs, mostly by professional experts, to one based on capabilities, rights and constructing effective relationships in schools through education consortia. It would also begin to break the cultural relationship between political and professional dependency. Only then will students with learning disability find flexible pathways in, through and from school that leads them on to realise the kind of life they want.


As a counter narrative to exclusionary discourses the voice of the young people with learning disability together with the narratives of this PAR journey has demonstrated that these young people are optimistic, insightful and capable. This thesis has been a journey of personal and professional, individual and collective discovery. Answers to what a good life means for young people with learning disability are to be found in how we fundamentally value this group of young people in education and society. Valuing can only occur if we recognise our interdependency while acknowledging our unique differences. Only then will we truly provide the opportunity and the forms of support that moves us all forward in our journey towards a good life.

Bauman tells us that “The carrying capacity of a bridge is measured not by the *average* strength of its pillars, but by the strength of the *weakest* among them; and so is the “carrying capacity” of society, that is, its humanity ... (2007, p. 58). The overwhelming realisation for me through this research journey has been the reality that the technical, traditional relationship has not worked and that it is only through a socio-ethical relationship that we can truly transform education and society to embrace all young people.

APPENDICES

Appendix A – Student information and consent form

Student Information and Consent Form 'My Life When I leave School' Transition Project

We want you  to take part in a Research Project

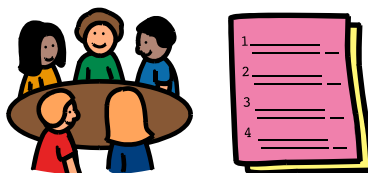
What do we want to know?



- We want to ***FIND OUT*** what kind of life you want.



We are going to do this by talking to people in small groups
and using questionnaires



1. This project has ethical approval from the **Health and Disability Upper South A Committee** and the **University of Canterbury College of Education Ethical Clearance Committee**.
2. Complaints may be addressed to:
Dr Herb de Vries (email: herb.devries@canterbury.ac.nz)
College of Education, University of Canterbury

(Appendix A continued)



Who will be asked to take part?

There will be students at school and young people who have left school

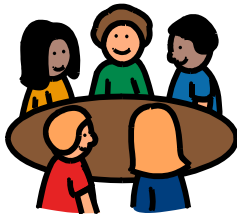
**WE WANT TO TALK WITH YOU 3 TIMES
AND OTHER YOUNG PEOPLE 2 TIMES**

Who is doing the research?



The Research Team has:

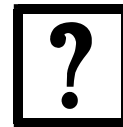
Colin Gladstone Andrew Dever Caroline Quick



How will the research be done?

We want to talk in a Focus Group Interview

We want to talk to you for about **2** hours, **3** times over the next year



What will happen with what is said?

What you say is important and may help to give you more choice and the kind of life that you want

(Appendix A continued)

‘My Life When I Leave School’ Transition Project

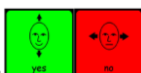
**If you want to take part please sign the consent form below and
also fill in a registration form.**

Student/ young adult CONSENT FORM

Please read this form with someone who knows you well and if you are happy about what it says, sign it and post it in the stamped, addressed envelope provided. Your parents/caregivers also sign a consent form for you.

- We will talk about what makes a good life?

- You will be asked some questions



- What is said will be recorded



You don't have to answer every question ?

- You can decide if you want to take part in the group.



- What is said in the focus group is private to us



- During the focus group you can:
 - Ask for the question to be said again
 - Ask for the tape recorder to be turned off.
 - Ask any questions or ask for any help.

You can contact **Colin, Andrew or Caroline** on **03 351 6743** or email:
gladbrick@yahoo.co.uk

if you have any questions or concerns about the focus group or this consent form.

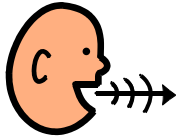
I know why we are having the focus group.

Name: _____ **Date:** _____

(Appendix A1 –invitation to second young adult focus group)

‘My Life When I leave School’ Transition Project

**Young Adult’s Focus Group
Friday 3rd December 2010**

We want to talk  **with you again**



We want to

find out from YOU  **what kind of life you have and what
you want to do in the future?**

Appendix B1 – Parent information sheet

Parent/Caregiver Information Form for son/daughter to participate in the

‘My Life When I leave School’ Transition Project

Hello, my name is Colin Gladstone and we are conducting a research project. Two young people Andrew Dever and Caroline Quick and I are working as a research team and we are finding out what students and young people do when they leave school and what choices they have about their future lives. We are trying to understand what they think is a good life for them as they transition from school. **It is hoped that the research will inform post school outcomes for young people with learning disability.**

We want students to have more choice and make decisions in what happens to them at school and also when they leave school. This might help them to lead happy and successful lives as they become adults. We would like to talk with your son/daughter about this at a focus group where we can hear their ideas and thoughts.

In highlighting the ‘voice’ of young people with disability we will talk with them three times over the coming year and other young people who have left school twice.

We will be recording the focus group discussions on a digital audio recorder to help remind us of their views and perspectives. The findings will be presented to the Minister of Education. What they say will form part of my University doctoral degree and work from the project might be published. Your son/daughter name will not be used and anything they say will be strictly confidential.

1. This project has ethical approval from the **Health and Disability Upper South A Committee** and the **University of Canterbury College of Education Ethical Clearance Committee**.
2. Complaints may be addressed to:
Dr Herb de Vries (email: herb.devries@canterbury.ac.nz)
College of Education, University of Canterbury
Private Bag 4800, CHRISTCHURCH Telephone: 345 8312 ext: 8638

If you would like further information on this project and the focus group please contact the research team c/o Colin Gladstone tel: 03 351 6743 ext 310, mob: 0210445874 or email: gladbrick@yahoo.co.uk

If you agree for your son/daughter to take part in this project please sign the consent form and put it in the stamped addressed envelope provided and further information will be sent about dates and times for the focus group, and on the day arrangements.

Yours sincerely,

Colin Gladstone, Caroline Quick & Andrew Dever.

Appendix B2 – Parent consent form

Parent/Caregiver Consent Form for son/daughter to participate in the

‘My Life When I leave School’ Transition Project

Please read this form and if you are happy about what it says, sign it and put it, with your son/daughters consent and registration forms, in the stamped addressed envelope provided.

I know:

- The group will be talking about what your son/daughter think is important about their life now and when they leave school.
- They will be asked some questions.
- What is said will be recorded.
- They don't have to answer every question.
- They can decide if they want to take part in the group.
- While confidentiality cannot be guaranteed, they must not pass on comments made in the focus group to other parties.
- During the focus group they can:
 - Ask for the question to be said again
 - Ask for the tape recorder to be turned off.
 - Ask any questions or ask for any help.

You can contact Colin Gladstone on 03 351 6743 if you have any questions or concerns about the focus group or would like further clarification.

- I agree / do not agree* for my son/daughter* to participate in the Focus Groups

Son/daughter name:

Parent/Caregiver name:

Signature:

Date

Appendix C – Principal BOT request information sheet Information Sheet

School Principals and Board of Trustees

Dear

‘My Life When I leave School’ Transition Project

Hello, my name is Colin Gladstone and I am conducting research project. Two recent school leavers, Andrew Dever and Caroline Quick and I, are working as a research team and we are finding out what students with learning disability do when they leave school, what choices they have and what they consider a good life to be. We are trying to improve the transition experiences for these young people to post school life. We are exploring what a good life is from their perspective.

We want students to have more control and pathways when they leave school.

In highlighting the ‘voice’ of young people with learning disability we will talk with them three times over the coming year and young adults who have left school twice.

We would like your school to have the opportunity to participate through the involvement in focus group discussions by some of your students over the next year. We respectfully ask if we might provide student invitations to participate in the research through [name deleted] at your school.

This project has received ethical approval from the Health and Disabilities Ethics Upper South A Committee as well as the University of Canterbury, College of Education Ethics Committee.

If you would like further information on this project please contact the research team c/o Colin Gladstone tel: 03 351 6743 ext 310, mob: 0210445874 or email: gladbrick@yahoo.co.uk

Yours sincerely,

*Colin Gladstone
Caroline Quick
Andrew Dever*

Appendix D – Focus group questions

Questions for Student Focus Group Number 2 – 26.06.09

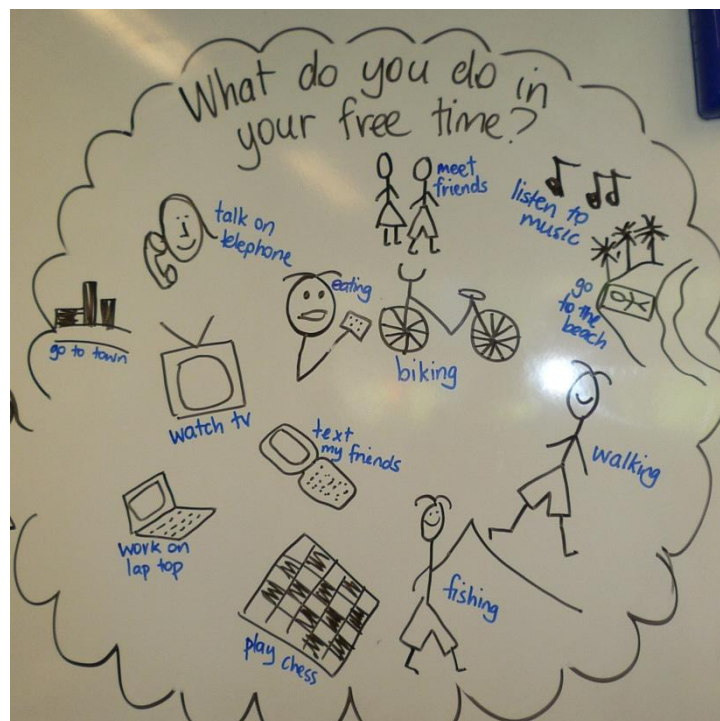
Andrew	<ul style="list-style-type: none"> • What do you want to do when you leave school?
Colin	<ul style="list-style-type: none"> • What is important to you in your life?
Andrew	<ul style="list-style-type: none"> • What choices do you make in your life?
Caroline	<ul style="list-style-type: none"> • Do you live with your parents?
Colin	<ul style="list-style-type: none"> • Will you always live with your parents?
Andrew	<ul style="list-style-type: none"> • What is a friend?
Caroline	<ul style="list-style-type: none"> • Do you have many friends?
Colin	<ul style="list-style-type: none"> • What do you do for leisure?
Andrew	<ul style="list-style-type: none"> • What clubs do you belong to?
Caroline	<ul style="list-style-type: none"> • Do you feel part of the community?
Colin	<ul style="list-style-type: none"> • Do you have a support or key worker?
Andrew	<ul style="list-style-type: none"> • Do you have your own money or allowance?
Caroline	<ul style="list-style-type: none"> • Are you doing any college/tertiary courses at the moment?
Andrew	<ul style="list-style-type: none"> • Do you go on holiday?
Caroline	<ul style="list-style-type: none"> • Do you go on holiday with your family?
Colin	<ul style="list-style-type: none"> • Do you have a part-time job? Do you get paid?

Appendix E – Focus group graphic illustrations

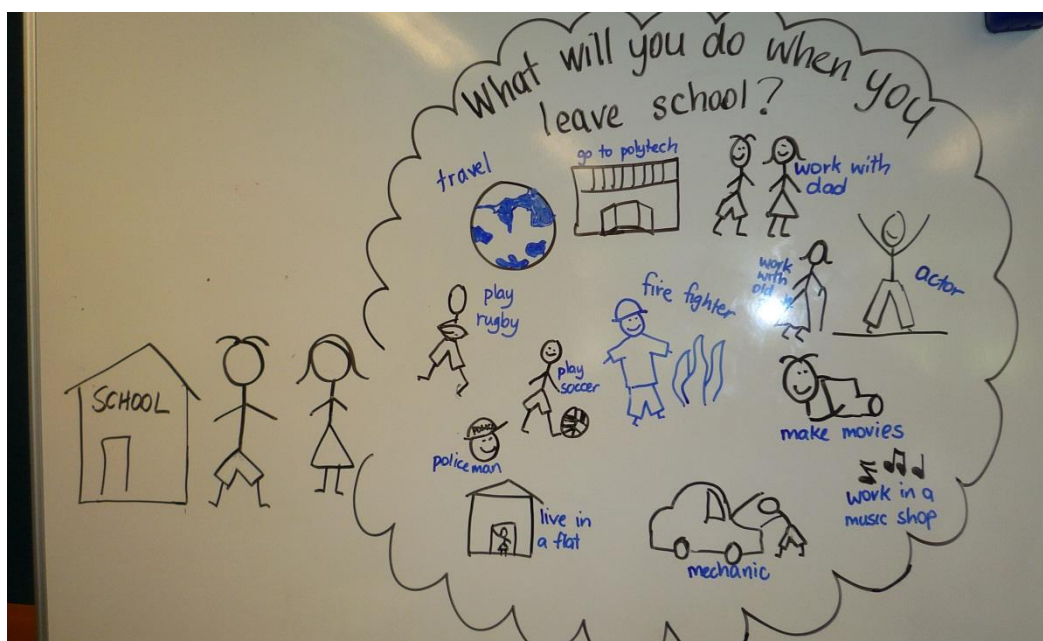
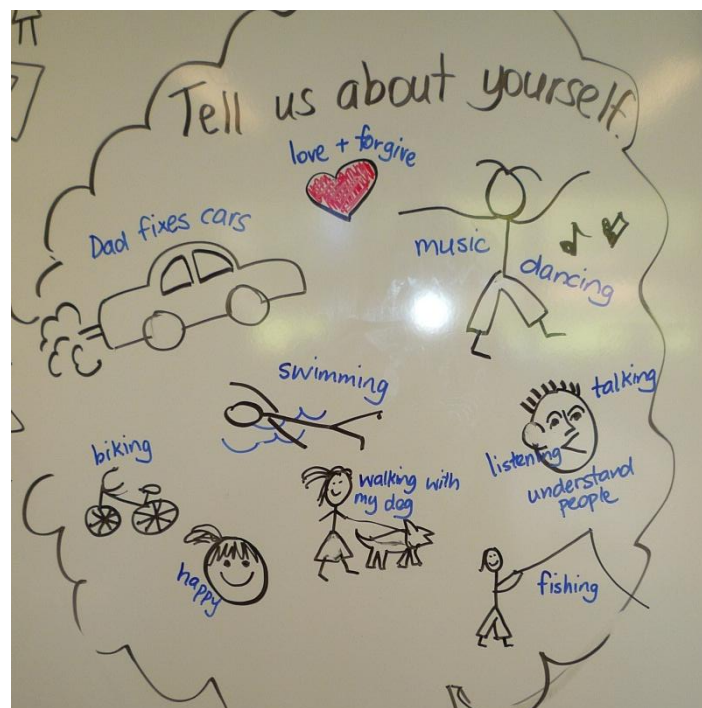
Examples



(Appendix E continued)






(Appendix E continued)






Appendix F – Student Questionnaire Questions

Are you happy?

 Yes	 No	 Don't know?
---	--	--




Comments:

Are you friendly?

 Yes	 No	 Don't know?
---	--	--




Comments:

Do you make choices?

 Yes	 No	 Don't know?
---	--	--

Comments:




Do you live with your parents?

 Yes	 No	 Don't know?
---	--	--

Comments:




(Appendix F continued)

Will you always live with your parents?

 Yes	 No	 Don't know?
---	--	---




Comments:

Do you want to get married?

 Yes	 No	 Don't know?
---	--	---




Comments:

Are you happy with your life?

 Yes	 No	 Don't know?
--	---	--




Comments:

Do you have many friends?

 Yes	 No	 Don't know?
---	--	---

Comments:




Do you want a paid job?

 Yes	 No	 Don't know?
---	--	---

Comments:




(Appendix F continued)

Do you feel important?

 Yes	 No	 Don't know?
---	--	---




Comments:

Do you feel part of the community?

 Yes	 No	 Don't know?
---	--	---




Comments:

Do you make decisions?

 Yes	 No	 Don't know?
---	--	---




Comments:

Do you go to a club?

 Yes	 No	 Don't know?
---	--	---

Comments:




Do you have a support worker?

 Yes	 No	 Don't know?
---	--	---

Comments:




(Appendix F continued)

Do you have your own money?

 Yes	 No	 Don't know?
---	--	---




Comments:

Do you have a job now?

 Yes	 No	 Don't know?
---	--	---




Comments

Are you doing any Polytech courses?

 Yes	 No	 Don't know?
---	--	---

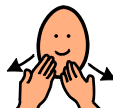
Comments:

Do you go on holiday?

 Yes	 No	 Don't know?
---	--	---

Comments:

Thank you very much



for completing this Questionnaire



Appendix G – Plain language initial student findings

‘My Life When I leave School’ Transition Project

Plain Language

Student Focus Groups Initial Findings

What makes you happy?

- Family and friends
- Being part of the community
- Having opportunities for further education and training
- Having hobbies and interests
- Being understood for who you are
- Having more control over your life, making choices and decisions

What is important?

- People are important like family, friends and teachers
- Having people to inspire you
- Planning for a career
- Having a paid job
- Having your own possessions
- Taking responsibility for yourself
- Moving away from family home
- Helping others
- Having new challenges

Making decisions?

- You all felt that you are an important person
- You know that as you get older you make more decisions in your life
- People help you make decisions

(Appendix G continued)

- You felt other people make decisions for you

When you leave school?

- Nearly all of you wanted a job or to go on to further education and training
- Some wanted to move away from family home and go flatting with friends
- Spend time with your friends, go on holiday

Getting ready for leaving school?

- You have done college courses, work experience, practised life skills
- You recognised that it takes time to get ready to leave school
- Take things step by step

Will you be able to do what you want?

- All of you felt that you will be able to do what you want when you leave school
- It might take a long time
- You will need help to get there
- But you want the chance

Appendix H – Plain language summary of findings

The ‘My Life When I Leave School’ Transition Project

Plain language summary of findings

WHAT YOUNG PEOPLE WITH LEARNING DISABILITY THINK

Research Team: Co-investigators – **Andrew Dever, Colin Gladstone & Caroline Quick**

We are a team of researchers who did research with **students and young people with learning disability**. ‘Research’ in this project means trying to find out things by **listening** to what people want.

What were we trying to find out?

We were trying to find out what a good life means for students and young people and what is important to them as they transition from school to post school life.

Why?

Because the young people **do not** usually:

- have paid work
- go on to tertiary education
- live away from the family home



- have many friends

have much say in what kind of life they have

➤ (Appendix H continued)

How?

We listened  to:

Students who were still at school

Young people who had left school aged 19 to 25 years

We listened to students and young people in **focus groups** over one year. We held 3 student and 2 young adult focus groups. We also used a questionnaire for information.

What we found out:



➤ The young people want the opportunity to do the same things that other young people can do like:

- Make decisions about their life
- Go to work and be paid
- Do tertiary study that gives them a career
- When ready - live away from the family home with people they like



➤ Most young people were **NOT** doing what they wanted to

(Appendix H continued)

- The young people know that doing tertiary short courses and work experiences while still at school
- will help them to make better decisions and have a better future

- The young people don't feel part of their community and that paid work and more training and skills would help

- The young people thought that family, good friends, work and helping other people are the most important things in life

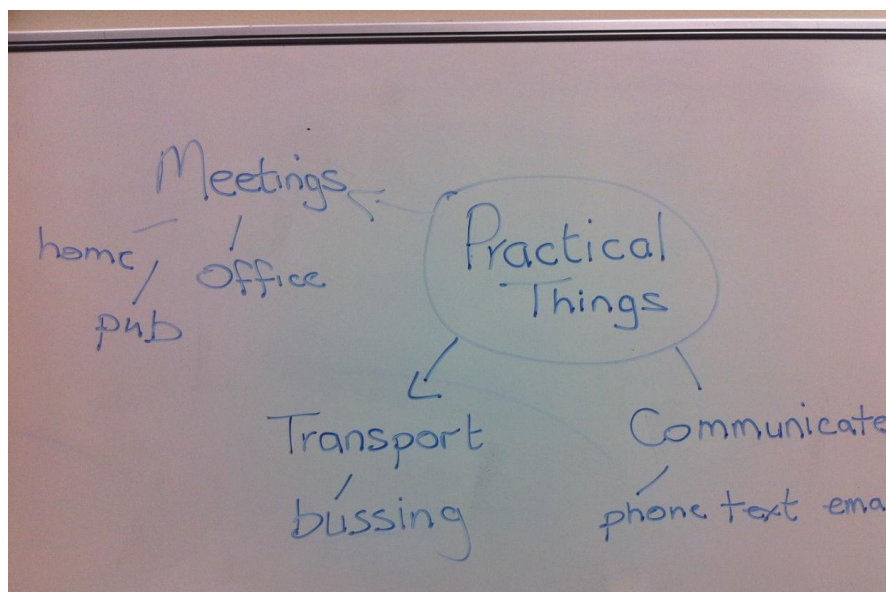
- The young people know that achieving these things will take time over a few years and that they will need support

- The young people want a GOOD life

For further information contact: Andrew, Caroline or Colin at gladbrick@yahoo.co.uk

Appendix I – Research themes analytical process

The graphics below demonstrate how the research team arrived at the themes for the Relational Dimension through discussion at team meetings. The theme 'Roles and Responsibilities' originated from the sub theme 'what I'm good at'. Similarly, the theme 'Logistics' originated from a discussion on 'practical things'.



Appendix J - Graphic representation of data analysis process

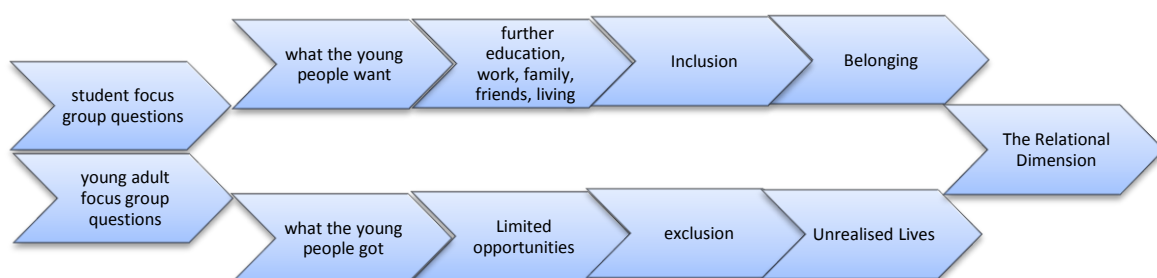
Framework for research aims and questions that led to ongoing iterative analysis

What is a good life from the young people's perspective?	
What are students doing at school?	What do students want to do after school?
What are young adults doing after school?	Why?
What is important to the students?	What is important to the young adults?
What helps?	What gets in the way?
Who helps?	Who gets in the way?

Iterative data analysis process



Moving from research questions to themes



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